INCORPORATING PUBLIC VALUES AND TECHNICAL INFORMATION INTO HEALTH CARE RESOURCE ALLOCATION DECISION-MAKING

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EXECUTIVE SUMMARY

Objectives

1. To synthesize existing research on factors considered during health care resource allocation decision-making, and assess its utility (i.e., impact on policy). These factors include public values, health law and legislation, and health technology information.
2. To assess the current and potential influence of "public values" on local priority-setting in Alberta
3. To identify options for obtaining the information required in order to incorporate public values along with evidence into local resource allocation decisions

Methods

1. A comprehensive, systematic literature review of published, peer and non-peer reviewed literature, as well as grey literature, was completed. To accomplish this, detailed search strategies were applied to 14 bibliographic sources. Additional citations were identified through manual searches, and relevant review articles.
2. To assess whether or not the literature reviewed influenced relevant policy, corresponding authors of published, peer-reviewed (i.e., not grey literature) papers on priority-setting processes and/or eliciting public values/opinions were sent surveys, via e-mail, fax, or post (depending on contact information provided in the papers). Three attempts to contact each author were made.
3. To examine current priority-setting processes within Alberta and determine the extent to which they involve the public, a demographically representative sample of Regional Health Authorities (RHAs) (8 out of 17) and all 3 provincial Boards/Committees were selected to participate in key informant interviews. Three members from each of these 11 bodies were interviewed: 7 CEOs, 1 Executive Vice-President, 7 Board Chairs, 1Vice-Chair, and 8 Medical Directors from the RHAs, and 1 CEO, 3 Board Chairs and 5 committee members from the provincial Boards/Committees. The interview contained 7 open-ended questions addressing how priorities are set and opportunities, if any, for public involvement in the process. Interviews were audio-taped and transcribed. Their content was then verified by performing member checks with a sample of key informants. Through a series of iterations, transcripts were analyzed using content analysis.

Results

1. Of 14 591 papers initially identified by the literature search, 117 were selected for full review and, subsequently, classified into one of three categories: actual (e.g., processes actually instituted), hypothetical (e.g., demonstration projects) and conceptual. Forty-nine papers described priority-setting at the health care system level (where choices must be made among competing services for different diseases and conditions). In general, they focused on approaches employed at the national or state level which resulted in the establishment of a list of principles or factors to be considered during priority-setting. However, those that outlined approaches employed at a regional level typically described techniques for generating an explicit, prioritized list of health care services (e.g., Programme Budgeting and Marginal Analysis) Sixty-eight papers presented methods for eliciting public values to

inform resource allocation decision-making. These methods included: ranking of services or programs, rating of options using Likert-type scales, making explicit choices between options, individual interviews, a Delphi process, focus groups, citizens' juries and town hall meetings. Based upon the literature reviewed, no single "generic" approach has been identified as the gold standard. Further, selection of which approach to use required consideration a variety of population-specific factors.

2. Twenty-seven legal cases relating to resource allocation were reviewed. Most of them described challenges to the Charter of Rights and Freedoms, malpractice suits, or the restructuring of hospital services. Decisions were made either by the Supreme Court of Canada, provincial Courts of Appeal or Trial Courts. Key questions underlying such decisions included whether health care providers and health services are governed by or protected under the Charter, and were resolved by applying the Charter. With respect to malpractice suits, the evidence provided during trials appeared to be non-existent, or at best, sketchy and anecdotal. Nonetheless, Courts have commented on the importance of not sacrificing individual or group welfare for resource allocation reasons, although they have yet to explicitly discuss the repercussions of enforcing these entitlements on health care systems.

3. Authors of 27 of the 30 (90% response rate) published, peer-reviewed papers on priority-setting and authors of 58 of the 68 papers (85% response rate) on eliciting public values/opinion responded to the survey by completing and returning questionnaires. Both groups were deemed representative of the populations surveyed. For the priority-setting literature, 89% of the authors reported that they knew decision-makers who were aware of their papers. In contrast, for the literature on eliciting public values, this was indicated by only half (n= 29) of the authors. Nevertheless, authors' responses regarding the ways in which information was used by decision-makers were similar across literature types. They included: for developing or revising priority-setting criteria/guidelines, to stimulate discussion about current priority-setting policies, as a guide for implementing a priority-setting framework, to support a current government policy/position, and to form the basis for a priority-setting "pilot" study. The two key reasons for using the information were: the paper had been done as a result of a request by decision-makers, and findings supported current government policies.

4. Key informant interviews with local decision-makers indicated that the most common approach used by RHAs to engage the public in priority-setting has been the creation of advisory groups (e.g., Community Health Councils). All 3 provincial Boards/Committees haven't yet directly involved the public in their priority-setting decisions. Nevertheless, the majority of those interviewed from both RHAs and provincial committees viewed input from elected Board members as "public" input. Further, during actual priority-setting, two types of public values-based "evidence" were identified: information from formal needs assessments and the Board's awareness of the public's acceptability or support of a specific "need". Within RHAs, priority-setting decisions were communicated directly to health care providers and indirectly to the public through the media. In contrast, provincial boards/committees were found to rely exclusively on the media. In general, key informants considered current processes to be fair, from a public health perspective, but agreed that

better ways of involving the public, which prevent domination by "special interest" groups, need to be examined.

Conclusions/Recommendations

Based upon the results, recommendations include:

1. A two-day decision-makers' forum to share the results of this review and develop a consortium between decision-makers and researchers to identify and conduct demonstration projects

2. Further research on a) economics-based approaches, b) techniques for collecting and analyzing data from priority-setting studies, c) and the willingness of individuals to participate in research that might involve trade-offs between population sub-groups

3. Surveys to determine decision-makers' views on existing research gaps and to establish the utility of commissioned reports during priority-setting

4. A more detailed, focused review of public involvement literature

INTRODUCTION

The current growth in new medical technologies and services that offer improved therapeutic and diagnostic options continues to place huge demands on Canada's publicly-funded health care system. This was most recently pointed out in various federal and provincial health reform reviews completed within the past several months. At the same time, government revenues have not kept pace with this growth. As a result, those making resource allocation decisions in health care face the challenge of deciding which technologies and services to offer. In response to this challenge and the well-recognized need for a system in which efficiency and equity are both achieved, there has been a global shift towards "evidence-based policy making" in health care. More recently, with the rise in public awareness of, and more importantly, interest in health care issues, it has become obvious that evidence, by itself, cannot drive priority-setting policies. The views of citizens who expect an accountable public system must also be considered.

This study was conducted as part of a series of proposals for "State of the Science Reviews" commissioned by the Alberta Heritage Foundation for Medical Research. The overall purposes of the study were to develop options for incorporating public values (alongside evidence) into health care priority-setting in Alberta, and to identify gaps in research in this area.

OBJECTIVES

Specific objectives were:

1a. To provide a synthesis of existing research conducted to identify and/or measure the influence of factors considered during resource allocation decision-making. Such factors include public values, health law policy and legislation (as mechanisms through which public values are upheld), and health technology information (i.e., evidence)

1b. To evaluate the quality (i.e., methodological validity) of the research synthesized and assess its utility (i.e., impact on policy)

2. To determine the current and potential influence of public values on local priority-setting processes from the perspective of health-care decision-makers in Alberta.

3. Based upon the research synthesized and the views of provincial health policy-makers, to formulate possible options for obtaining the information required in order to incorporate public values, along with evidence, into local resource allocation decisions.

METHODS

1. Literature synthesis

A comprehensive search for peer and non-peer reviewed, English language literature, as well as grey literature and documents of court decisions, published before November 2002 was completed. Prior to conducting the literature search, critical terms describing resource allocation decision-making, health care priorities, and public values were identified. These terms (free text and truncated), along with their likely synonyms, were first verified by examining the list of controlled vocabulary terms (e.g., medical subject heading (MeSH) terms) used to index already-known key references and then combined to form a structured search strategy reflecting important conceptual relationships between terms.

The search strategy was applied to the following electronic bibliographic databases, covering biomedical, social science, and health policy and management topics: PubMed / MEDLINE, HealthSTAR, CINAHL, PsycINFO, EconLit, the Centre for Reviews and Dissemination databases (HTA, NHS EED, and DARE), Dissertation Abstracts International, and Web of Science (Science Citation Index, Social Science Citation Index, and Arts and Humanities Index). Unpublished or non-peer-reviewed information (e.g., conference proceedings, technical papers, and government sponsored reports) were identified through internet searches using meta-browsers capable of scanning multiple file formats (e.g., PDF files). In addition, a series of reference databases designed specifically to capture "grey literature" were employed. These included: SIGLE (System for Information on Grey Literature in Europe), Cabot (comprising unpublished and published Canadian health services research literature), AMICUS (the National Library of Canada union catalogue of government and university library holdings), the National Library of Medicine's Gateway, NTIS (the United States National Technical Information Service) and the New York Academy of Medicine Grey Literature Page (which contains a list of organizations and agencies producing grey literature on health policy and public health). For completeness, the electronic search was supplemented by a manual search of reference lists from articles selected for retrieval and recent literature reviews on 1) priority-setting in hospitals and 2) legal and policy issues related to health care reform authored by members of this proposal's research team. An analysis of MeSH terms applied to index these articles and text words contained in their titles and abstracts was also performed. This information was then used to refine the initial search strategy and rescan the databases listed above for previously unidentified citations.

Relevant legal literature was identified through an electronic search of the Canadian Judgements Case Law Database, supplemented by a manual review of leading health law and policy text books, as well as survey articles.

Results of both the electronic and manual literature searches were imported into Reference Manager Version 10.0. After removing duplicate entries, a total of 14 591 citations remained (Table M1). The relevancy of these citations was assessed in 2 stages by 2 independent reviewers.

Table M1. Summary of literature search results according to the electronic database employed

Type of literature	Bibliographic database	Search strategy	Number of citations identified
Published, peer-reviewed	PubMed / MEDLINE	(data collection or decision making OR evaluation OR evaluate* OR appraisal OR appraise* OR qualitative analysis) AND (prioritiz* OR prioritis* OR priority setting OR resource allocation OR health care rationing); (method* OR guideline* OR instrument* OR tool*) AND (prioritiz* OR prioritis* OR priority setting OR resource allocation OR health care rationing); (financial management OR health care rationing OR health care reform OR health priorities OR resource allocation of health care OR priority setting) AND (public policy OR public values OR public opinion OR public involvement OR values ((public OR consumer OR citizen OR community) AND (consultation OR participation))	16 170
Published, peer-reviewed	HealthSTAR	(exp evaluation/ OR "evaluation".mp OR exp data collection OR "data collection".mp OR "qualitative analysis".mp OR exp decision making/ OR "decision making".mp OR "appraisal".mp OR "priority setting".mp OR "prioritization".mp) AND (guideline$".mp OR method$".mp OR exp methodology/ OR "methodology".mp OR "instrument$".mp) AND ("financial management".mp OR "health care rationing".mp OR exp resource allocation/ OR "resource allocation".mp OR "health care reform".mp OR "public involvement".mp OR "community involvement".mp	1779
Published, peer-reviewed	EMBASE	(exp evaluation/ OR "evaluation".mp OR exp meta analysis OR "qualitative analysis".mp OR "appraise".mp OR "evaluat$".mp OR exp information processing/ OR "data collection".mp OR exp decision making/ OR decision making".mp) AND ("instrument$".mp OR "tool$".mp OR "guideline$".mp OR exp technique/ OR "method$".mp) AND (exp financial management/ OR "financial management".mp OR "health care rationing".mp OR exp health care policy/ OR "health care reform".mp OR exp health care planning/ OR "health priorities".mp) AND ("public policy".mp OR "public values".mp OR "social values".mp OR "consumer participation".mp OR "public opinion".mp)	2446

Table M1. continued

Type of literature	Bibliographic database	Search strategy	Number of citations identified
Published, peer-reviewed	PsycINFO	(exp evaluation/ OR "evaluation".mp OR exp data collection OR "data collection".mp OR "qualitative analysis".mp OR exp decision making/ OR "decision making".mp OR "appraisal".mp OR "priority setting".mp OR "prioritization".mp OR prioritisation".mp) AND ("guideline$".mp OR "method$".mp OR exp methodology/ OR "methodology".mp OR "instrument$".mp) AND ("financial management".mp OR "health care rationing".mp OR exp resource allocation/ OR "resource allocation".mp OR "health care reform".mp OR "allocation of health care".mp OR "health priorities".mp) AND "public policy".mp OR "public values".mp OR citizen participation".mp OR "consumer participation".mp OR "public opinion".mp OR "public opinion".mp OR "public involvement".mp OR "community involvement".mp OR "public consultation".mp)	75
Published, peer-reviewed	EconLit	(health care reform OR health care rationing OR resource allocation OR priority setting OR decision making) AND ((method OR guideline OR tool OR instrument OR evaluation) AND (public opinion OR public values OR consumer participation OR public participation OR social values OR public policy OR public involvement))	29
Published, peer-reviewed	CINAHL	(exp evaluation/ OR "evaluation".mp OR exp data collection OR "data collection".mp OR "qualitative analysis".mp OR exp decision making/ OR "decision making".mp OR "appraisal".mp OR "priority setting".mp OR "prioritization".mp OR prioritisation".mp) AND ("guideline$".mp OR "method$".mp OR exp methodology/ OR "methodology".mp OR "instrument$".mp) AND ("financial management".mp OR "health care rationing".mp OR exp resource allocation/ OR "resource allocation".mp OR "health care reform".mp OR "allocation of health care".mp OR "health priorities".mp) AND "public policy".mp OR "public values".mp OR citizen participation".mp OR "consumer participation".mp OR "public opinion".mp	490

Table M1. continued

Type of literature	Bibliographic database	Search terms applied	Number of citations identified
Published, peer-reviewed	Centre for Reviews and Dissemination databases	((health AND care AND rationing) OR (health AND care AND reform)) AND ((financial AND management) OR ((public AND opinion) OR (public AND values) OR (public AND involve) OR (social AND values))	133
Published, peer-reviewed	Dissertation Abstracts International	health care AND public participation; health care AND consumer participation; Health AND resource allocation; Health AND rationing; values AND health AND decision making; resources AND health AND decision making	387
Published, peer-reviewed	Web of Science	public values AND (decision making OR health care rationing OR health care reform OR priority setting OR health care rationing OR resource allocation); health AND (resource allocation OR decision making)	1295
"Grey"	AMICUS	citizen participation AND health AND decision making; citizen participation AND reform AND health; public values AND health AND decision making	
"Grey"	NLM's Gateway	"resource allocation" AND "public participation" AND "decision making"; health care reform (MeSH OR key word) AND consumer participation (MeSH OR key word); "health care rationing" AND "consumer participation" AND "decision making"; (decision making OR qualitative analysis OR prioritization OR prioritization) AND (health care reform OR health care rationing OR resource allocation) AND (public policy OR public values OR consumer participation OR public)	1002
"Grey"	NTIS	Public values; public opinion; public policy; resource allocation; health care reform; health care rationing; priority setting; consumer participation; community participation; health care reform AND decision	469

Table M1. continued

Type of literature	Bibliographic database	Search terms applied	Number of citations identified
"Grey"	New York Academy of Medicine Grey Literature Page	health care resource allocation OR priority setting OR health care rationing; (public values OR public involve*) AND (resource allocation OR priority setting OR health care rationing)	37
Case Law	Canadian Judgements Database	Data collection AND prioritis OR prioritiz!; data collection AND priority setting OR resource allocation OR health care rationing; decision making AND prioritis! OR prioritiz' OR resource allocation OR health care rationing; financial management OR health care rationing OR health care reform AND public policy OR public values OR public opinion; financial management OR health care rationing OR health care reform AND public OR consumer OR citizen OR community; financial management OR health care rationing OR health care reform AND public involvement OR social values; health care rationing; health care reform; resource allocation	460
Total (before removing duplicates)			24 772

The initial scan, which involved reference titles only, resulted in the selection of 1192 citations for further consideration. Importantly, those discussing program-specific or disease-specific priority-setting (which does not require consideration of how best to distribute resources across all types of health services) (e.g. papers on priority-setting for cancer drugs), patient-level resource allocation, public satisfaction polls, or patient involvement in clinical decision-making were excluded. Abstracts corresponding to these 1192 citations were then obtained and scrutinized by the same two reviewers. Upon resolving discrepancies, 315 references were selected for retrieval. Following a review of all 315, 117 were selected for inclusion in the analysis. Those excluded comprised "opinion pieces" (e.g., commentaries, editorials, etc.) and papers which did *not* specify a *model or an approach* to priority-setting or eliciting public values. The remaining 117 were classified according to whether they dealt with priority-setting or with eliciting public values/opinion, and then, categorized into three groups: *actual*, *hypothetical* and *conceptual* papers.

Searches for relevant legal literature initially identified 460 citations, of which only 27 were selected for full review. They included cases directly or tangentially related to resource allocation.that involved the highest level of court decisions.

Information from articles were systematically collected using data abstraction or coding forms (Appendix A). Before beginning data collection, these forms were pilot tested on a representative sample of 10 articles by the two reviewers who abstracted data for the main study. This process allowed for inconsistencies in the interpretation of the forms and inadequacies in the protocol, itself, to be identified and rectified. At that point, a set of decision rules was also established. To minimize reviewer error, "inter-rater reliability" was assessed periodically throughout data collection.

The quality of papers presenting hypothetical approaches to priority-setting and/or eliciting public values was assessed by incorporating a series of quality appraisal questions/criteria into the data abstraction forms. Thes questions/criteria were adapted from peer-reviewed, published guidelines developed specifically to evaluate qualitative research in health care. These guidelines assess quality on the basis of validity and relevance. As such, they include questions pertaining to comprehensiveness of the data collected (*Was theoretical saturation or informational redundancy reached?)* and appropriateness of procedures used to analyze the data and corroborate findings (*Were findings triangulated using multiple information sources ?).*

To assess the quality of legal literature reviewed, both the legal/precedential weight carried by the decisions presented and the substance of the decisions were analyzed. Weight was determined on the basis of ranking by court level, year, and jurisdiction. To evaluate substance, the following questions were asked: What reasons were given for the judgement? Were resource allocation issues central or tangential to those reasons? Was position articulated on resource allocation issues? Was the position supported by evidence or data, and if so, what was it? Was the position supported by reference to legal or ethical principles and if so, what were they? Were "where do we go from here?" options explicitly stated?

2. Authors' Survey

An attempt was made to determine whether or not results from the appraised studies were used by health care decision-makers. To accomplish this, "corresponding authors" of *peer-reviewed, published* papers comprising the literature synthesis were sent a short, semi-structured survey, as well as an information letter, by e-mail, fax, or post, depending upon the correspondence address provided on the retrieved article. To ensure that the information letter and survey questionnaire were clear, they were pretested on 4 health services researchers with various degrees of publishing experience. Importantly, no authors of grey literature (e.g., commissioned/ official government reports) were surveyed since contact information was not typically provided in the papers, themselves. Authors who contributed more than one paper to the literature review were asked to complete a separate questionnaire for each one. The questionnaire included open-ended questions asking authors to describe how, if at all, their studies have impacted priority-setting within actual health regions (Appendix B). A two-week follow-up reminder to non-respondents, which involved resending both the questionnaire and information, was also performed. Upon receiving completed surveys, authors' responses were assessed using content analysis and presented in summary form.

While recognizing the susceptibility of this approach to reporting bias, the more desirable alternative, which would have involved an international survey of health care decision-makers, was not considered feasible within the required time-frame.

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3. Key Informant Interviews

Current priority-setting processes in local health care jurisdictions, as well as the extent to which public values are considered, were examined through key informant interviews involving 11 health care regulating bodies in Alberta. They included a demographically representative sample of regional health authorities (RHAs) (8 out of 17) and all 3 health-related provincial

Boards/Committees. To ensure participating RHAs represented regions across the entire province, RHAs were selected according to geographic location, budget size, and the presence/absence of high-risk communities. For comprehensiveness, three members from each of the 11 bodies were interviewed. In each RHA and provincial Board/Committee, separate, in-person (where possible), hour-long interviews were scheduled with the chief executive officer (CEO) (or equivalent), board chair (or designated alternative board member), and medical director (or equivalent) at their respective workplaces.

To ensure data collection was performed systematically, all 33 interviews (RHAs: 7 Chief Executive Officers and 1 Executive Vice-President, 6 Board Chairs and 7 Vice-Chairs, and 8 Medical Directors; Provincial Boards/Committees: 1 President, 3 Board Chairs, and 5 Board/Committee members) were conducted by the same interviewer. Pilot interviews were first carried out with the Chair of the Board of one RHA and the Executive Vice-President of another RHA. These were conducted by the interviewer and one of the investigators. The survey contained seven open-ended questions regarding how priorities are set and opportunities, if any, for the public to be involved in the process. Each interview lasted approximately one hour, and was audio-taped and then transcribed, thus minimizing the likelihood of misreporting any information. Copies of transcripts, as well as the information extracted from them, were sent to a sub-set of participants for their review (i.e., a series of member checks was performed). Through several iterations, transcripts were analyzed using content analysis. This involved identifying key "chunks" of information or themes (e.g., "data") and sub-themes (e.g., "data access") by hand. These themes arose entirely from post-hoc analysis (i.e., the concepts that emerged). All transcripts were interpreted independently by two individuals (the interviewer and a member of the project team) who then met to identify and resolve discrepancies.

RESULTS

1. Literature synthesis

Priority- setting and public values

The 117 papers reviewed were classified into two groups: those that presented priority-setting approaches (n=49) and those that addressed elicitation of public values/opinion regarding priorities for health care services/technologies (n=68).

Papers on priority-setting processes

The 49 papers were classified into three groups:
i) Reports of actual priority-setting ("actuals") (n=36)
ii) Reports of hypothetical examples (e.g., demonstration projects) ("hypotheticals") (n=6)
iii) Conceptual models/frameworks (n=7).

Thirty-six papers fell into **category (i)**. Twenty four described priority-setting approaches used at the national or state level (Table R1a) and 12 focused on methods used at a regional level (Table R1b). With respect to national/state levels approaches, most began with the assembly of a government-appointed committee charged with the task of developing a systematic process for priority-setting. Following extensive consultation with stakeholders, which employed various methods (see Table R1a), committees identified principles and factors that should be considered during priority-setting. In general, there were no significant variations between countries. For example, equity, solidarity, and equality appeared repeatedly, as did need, effectiveness/benefit, and efficiency. Further, none of the national/state level processes reviewed resulted in an explicit list of services to be funded. Instead, the majority proposed guidelines or criteria for priority-setting based on principles or factors such as condition/disease severity (see Table R1a). While this was also the case for several of the regional-level papers reviewed, some did present tools (e.g., Programme Budgeting and Marginal Analysis (PBMA)) that produced a defined or explicit list of priorities (e.g., programmes, service, or disease areas) (see Table R1b). In addition, the principles and factors considered by regions during decision-making appeared similar to those identified during national/state processes, although detailed descriptions were often not provided. In addition, most regions were found to engage the public at some point in the priority-setting process.

Six papers fell into **category (ii)** (Table R1c). All of them outlined methods for generating an explicit list of priorities. While 3 papers were based on pilot projects of well-established tools already used in priority-setting (e.g., PBMA, and QALYs), 2 presented new tools or new applications of tools used in other disciplines (discrete choice modeling and Basic Prioritization Index). However, both tools were deemed impractical by decision-makers involved, since they were conceptually difficult to understand and relied heavily on data (e.g., effectiveness, utilization, and cost, etc.) that were often not readily available to decision-makers

An attempt to assess the quality of the hypothetical papers was made. However, for most of the papers reviewed, the information was not presented in enough detail to allow for their appraisal using existing validated guidelines/criteria designed for qualitative research studies.

Seven papers fell into **category (iii)** (Table R1d). Five described possible frameworks/models for priority-setting. Suggestions included: a population-based needs assessment to determine relative allocations between communities, a "Benefit Review Board", a generic process for integrated delivery systems, a representative group assembled from the general public or patients (depending on the level of priority-setting), or use of the Canadian constitution or charter for health services as the main driver of the entire process. All 5 papers emphasized the need for public or community involvement, while pointing out that the "public" may have a number of different roles in the process, depending on the type or level of decision being considered. However, of those that outlined methods for achieving this, none provided the level of required in order to properly assess whether or not such suggestions could be easily operationalized. The remaining two papers outlined specific quantitative methodologies (adjusting the QALY for severity and potential health improvement, and the Program Budget and Marginal Analysis (PBMA) approach) that could be used to rank priorities. Since this project focused on priority setting, rather than on economic evaluation methodologies, papers dealing with other types of QALY adjustments or methods such as the Person-Trade-Off which did not specifically discuss their application in a priority-setting context, were excluded from the review. Thus, in brief, this set of 7 papers did not appear to offer strategies that could be immediately employed in local setting within Alberta.

Papers on elicitation of public values/opinion
The 68 papers were classified into three groups:
i) Reports of original data (n=42)
ii) Reviews of reports of original data (n=9)
iii) Conceptual/discussion pieces (n=17)

The primary studies described in **category (i)** used a variety of methods. These included:
a) Quantitative – Ranking (n=7)
b) Quantitative – Rating (n=10)
c) Quantitative – Choice based (n=9)
d) Qualitative – Individuals (n=5)
e) Qualitative – Groups (n=11)

Studies using a **ranking** method involved members of the public, representatives of organizations and physicians (Table R1e). Respondents were typically asked to rank-order sets of services or programs. Questionnaires, and in one case, a personal interview, were employed to obtain information from participants.

Participants in the **rating** studies included members of the public, patients, nurses, physicians, students and lay members of a health board/council. Most studies employed a Likert-type scale to elicit ratings, while one used a visual analog scale. (Table R1f).

Choice-based studies involved members of the general public, students, physicians, and staff of general practices. In most cases, the participants were asked to make an explicit choice between pairs of options. In one case, the standard gamble and person-trade-off methods were used (Table R1g).

Qualitative studies involving **individuals** primarily selected interviews as the means of obtaining participants' views. However, one study used conjoint analysis to generate scenarios for

consideration and another chose a two-round Delphi approach. Participants included patients, parents of primary and secondary school children and members of the public (Table R1h).

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state

Author	Year published	Description of Priority-Setting Approach: Priority-setting committee and/or other individuals involved	Process used to set /identify priorities	Data collection instruments/ tools used	Principles/factors considered	Final priorities identified	Conclusions/ outcomes
Austria							
Stepan & Sommersguter-Reichman	1999	*Priority-setting committee* None stated	*Informal* -none stated, but identified health policy goals as prioritization criteria	None stated	*Principles* -solidarity *Factors* -need -complexity -uncertainty -information asymmetries -cost-utility -cost-benefit	Priority criteria derived from 3 health policy goals (ranked) 1. equity 2. cost-effectiveness 3. clinical effectiveness	-equity criteria is embodied in law (i.e., illegal to offer different treatments based on age, incomes, or social class -cost-effectiveness studies not widespread, making it impossible to consider cost-effectiveness in consistent manner
Finland							
Rissanen	1999	*Priority-setting committee* None stated	*Informal* 1. Series of informal debates and discussions among health care professionals and researchers (partly carried out in media) resulted in recognition of need for prioritization 2. Finnish institutions held consensus meeting on priority-setting 3. Developed consensus statement outlining principles and factors requiring consideration and the need to assess effect of priority-setting decisions on population health	None stated	*Principles* -dignity -autonomy -equality -equity -universality *Factors* -need to ensure effective care and pain relief -expected health gain	Identified list of negative criteria (criteria not to be used) (not ranked) -age -gender -lifestyle	-no general rules for priority-setting established
Germany							
Busse	1999	*Priority-setting committee* Advisory Council for Concerted Action in Health Care (appointed by Federal Ministry of Health) comprising 7 experts in medicine and economics	*Formal* 1. Advisory Council used results of national public survey and two-round Delphi survey of physicians and experts to set rules for financing social services 2. Developed criteria for evaluating technologies/ services 3. Established decision options for Federal Committee of Physicians and Sickness Funds	*Public survey* -respondents given series of scenarios and asked to make choices between patient(s) *Delphi survey* -comprised of questions such as "which benefits should remain an essential part of social health?" and "are some benefits no longer justified based on the principle of solidarity and subsidiarity?"	*Principles* -solidarity -subsidiarity -equity	2 key principles identified to guide priority-setting (unranked): -equity -comprehensiveness	-developed 3 criteria for evaluating technologies/ services for coverage (ranked): 1. Benefit 2. Medical necessity 3. Efficiency -established 3 categories of decisions: 1. To be included/ retained in benefit package 2. May not be provided in State insurance 3. May only be provided by individual sickness funds

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state continued

	Year	Description of Priority-Setting Approach

Author	published	Priority-setting committee and/or other individuals involved	Process used to set/identify priorities	Data collection instruments/ tools used	Principles/ factors considered	Final priorities identified	Conclusions/ outcomes
Israel							
Chinitz et al	2000	*Priority-setting committee* Public committee (appointed by Ministry of Health) set up to suggest priorities for distributing annual allotment of funds	*Informal* -no formal process used -new services considered during scheduled "rounds" and those "rejected" may be re-submitted to future rounds -services approved by committee are accompanied by explicit clinical guidelines	None stated	*Factors* -cost-effectiveness	None stated	- committee suggested use of combination of explicit and implicit approaches to priority-setting
Netherlands							
Netherlands, Government of	1992	*Priority-setting committee* "Choices in Health Care" Committee (i.e., Dunning Committee) (appointed by government) set up to put limits on new technology and deal with scarcity, rationing, and necessity of care	*Formal* 1. Developed definition for health: "ability to function normally" 2. Examined normal function from 3 perspectives: 1) individual 2) medical-professional 3) community-oriented and determined that community approach should govern population-level priority-setting 3. Identified principles for basing guidelines 5. Developed 4-seive framework for identifying which services to include	None mentioned	*Principles* -equality of people -protection of human life -solidarity *Factors* -nature and severity of disease/condition -effectiveness of intervention -efficiency	Services meeting the following 4 criteria will be included in basic health care package: 1. Necessary 2. Effective 3. Efficient 4. Cannot be left up to individual responsibility (framework described as a funnel with four sieves)	3-step approach to setting priorities recommended: 1a. Identify categories of diagnosis/ treatment combinations based on nature and severity of condition and treatment effect 1b. Order categories according to community-oriented approach 1c. Determine necessary care on basis of political acceptability 2. Research ways to relate cost and effectiveness (initiative of Health Insurance Council) 3. Base final decisions on ability of services to meet 4 identified criteria -suggested increasing investment in health technology assessment -professional associations asked to prepare evidence-based guidelines to ensure appropriate use of resources

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state continued

Author	Year published	Description of Priority-Setting Approach: Priority-setting committee and/or other individuals involved	Process used to set/identify priorities	Data collection instruments/ tools used	Principles/factors considered	Final priorities identified	Conclusions/ outcomes
New Zealand							
Ham New Zealand, Government of Hadorn and Holmes Campbell Cumming	1997 1996 1996 1995 1994	*Priority-setting committee* National Advisory Committee on Core Health and Disability Services (appointed by government) set up to advise on relative priorities of health services that should be publicly funded (i.e., core services) -comprised of 8 members representing clinical, academic-medical, legal-ethical, Maori health, nursing, disability support, and consumer interests Other Individuals involved Identification of priority service areas: -public -special interest groups Consensus development conferences: -economists -ethicists -physicians (specialists and GPs) -patient representatives Public forums: -randomly selected members of public -Core Services Committee -health professionals -providers -purchasers	*Formal* 1. Identified priority service areas through public meetings, special interest group meetings, letters and submissions received from community, and surveys 2. Identified principles/factors deemed important to public based on above findings: quality of life, improved basic services, and community-based services 3. Held series of treatment or condition-specific consensus development conferences to establish intervention effectiveness and guidelines for provision of services -reviewed relevant literature -assembled advisory groups -identified criteria -conducted 2 stage Delphi survey to establish consensus 4. Held series of public forums to determine acceptability of service criteria (i.e., social factors that should be considered) 5. Held workshops with at-risk groups within community to identify ways of distributing health care fairly	Consensus development conference questions: 1. What are the benefits? 2. Is it value for money? 3. Is it fair? 4. Is it consistent with community's values? Public forum questions: 1. Should social factors be included in decisions about priority for services? 2. Should social factors be decided by health professionals? 3. What are the most important social factors? 4. To what extent should social factors influence decisions?	*Principles* For ranking interventions within identified priority service areas: -benefit -value for money -fair use of public funding -consistency with community's values *Factors* -effectiveness of intervention (i.e., expected improvement in health or disability status and evidence of service implications) -efficiency -stage of technology's development (those in early stages not be included in core services) -equity of access	Identified priority services areas: 1. Children's health 2. Mental health 3. Integrated community care 4. Emergency ambulance services 5. Rehabilitation 6. Hospice care Identified 6 principles that should "underlie purchasers' activities" 1. equity 2. effectiveness 3. efficiency 4. safety 5. acceptability 6. risk management	- developed system of rationing through guidelines -Ministry broadly defined services RHAs should purchase but left explicit decisions to RHAs

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state continued

Author	Year published	Description of Priority-Setting Approach					
		Priority-setting committee and/or other individuals involved	**Process used to set/identify priorities**	**Data collection instruments/ tools used**	**Principles/ Factors considered**	**Final priorities identified**	**Conclusions/ outcomes**
Norway							
Caltorp Holm	1999 1998	*Priority-setting committee* National Priority Commission (appointed by federal government) comprising health care experts and members of public	*Formal* 1. Identified 5 levels based on disease/condition severity and treatment benefit to direct development of priority-setting guidelines 2. Devised 4 guidelines 3. Developed implementation strategy involving formation of national-level, specialty-focused expert groups to determine how treatment categories should be handled	None stated	*Principles* -equity -fairness *Factors* -severity of disease/ condition -effectiveness of intervention	Identified disease/ condition severity-based criteria for developing priority-setting guidelines (ranked): 1. Life-saving and essential treatments 2. Treatments in less severe situations where withholding them would be harmful 3. Treatments for chronic disorders with proven benefit 4. Treatment with unclear benefits 5. Treatments that are neither needed nor have proven value	-established guidelines for priority-setting 1. Basic health services cost efficient, proven treatments and those for serious diseases should be covered 2. Additional health services: treatments with less definite outcomes and those for less serious diseases should be covered as far as possible 3. Low priority or borderline services: should only be provided if resources are left over 4. No priority and outside public funding: includes investigative research activities and experimental treatments
Spain							
Gaminde	1999	*Priority-setting committee* -Inter-territorial Council comprised of 17 regional health ministers and federal minister of health	*Formal* 1. Identified key priority areas: transplants, drugs, and AIDS 2. Identified criteria upon which health priorities in Regional Health Plans are based 3. Identified criteria for excluding services and including new services 4. Produced and circulated White Paper recommending legislative process for establishing basic benefits package	None stated	*Principles* -equity -freedom of choice -"complaints and reimbursement rights" *Factors* -need -social utility -cost-effectiveness -quality of care -waiting time	Identified health priorities criteria (unranked): 1. Extent and seriousness of problem 2. Availability of effective curative methods 3. Ability to use methods appropriately Identified criteria for excluding services 1. No evidence of clinical effectiveness 2. No proven impact on life-expectancy 3. Increase in patient self reliance 4. diminution of patient distress	-recommended establishment of a decree which: 1. Defines rights of citizens regarding health protection 2. Introduces procedures for continuous evaluation of new technologies and services, as well as existing ones -adopted criteria for including new services: 1. Safety 2. Efficacy 3. Efficiency

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state continued

Author	Year published	Description of Priority-Setting Approach: Priority-setting committee and/or other individuals involved	Process used to set/identify priorities	Data collection instruments/ tools used	Principles/factors considered	Final priorities identified	Conclusions/ outcomes
Sweden							
Caltorp Ham McKee & Figueras Swedish Government Official Report Ham	1999 1997 1996 1996 1995	Priority-setting committee -Swedish Priorities Commission (appointed by government) comprising representatives of leading political parties and central and local government Other individuals involved: -Attitude surveys of 4 key interest groups: 1. Public 2. Health professionals 3. Politicians and administrators 4. Doctors and nurses in Stockholm	*Formal* 1. Formed government-appointed committee to recommend guidelines for priority-setting 2. Reviewed priority-setting in other countries and consulted experts from other health authorities 3. Published and circulated a discussion document to stakeholder groups 4. Conducted regional meetings and attitude surveys 5. Established 3 ethical principles to guide priority-setting 6. Identified 2 categories of priorities in order to deliver practical advice: 1) clinical and 2) political and administrative	Public survey -asked about relative value of different forms of care and for different age groups Health professionals survey: -examined attitudes of nurses and doctors Politicians/ administrators survey: -examined ethical values and concepts of justice Health services management Survey: -asked doctors and nurses about potential impact of changes on health services management	*Principles* (ranked) -human dignity -need and solidarity -cost-efficiency (comparisons of interventions to be made only for the same disease group) *Factors* -severity of disease/condition -age Those not t to be considered: -self-infliction of condition/disease -social position -economic status	Identified clinical priorities 1. Treatment of life-threatening disease and those which, if left untreated, will lead to premature death and/or permanent disability 2. Treatment of chronic diseases and palliative terminal care 3. Individualized prevention and habilitation/ rehabilitation 4. Treatment of less severe acute and chronic disease 5. Borderline cases 6. Care for reasons other than disease or injury Identified political/ administrative priorities: Same as clinical priorities except life threatening diseases combined with chronic diseases	-recommended creation of advisory committee on prioritization comprised of professionals and lay members -proposed legislative changes to ensure ethical principles guide priority-setting -established new commission to monitor and evaluate effects of priority-setting decisions and compare Sweden's experiences to those abroad
United Kingdom							
Ham Newdick	1997 1995	*Priority-setting committee:* No government-sponsored national committee	*Informal* 1. Local policy makers select resources based on proven effectiveness 2. Invested in health technology assessment 3. Developed clinical practice guidelines to ensure resources used effectively Formal processes 1. Program Budgeting and Marginal Analysis used by some regional health authorities	None stated	*Principles* (used informally by local policy makers) -equity -responsiveness *Factors* (used informally by local policy makers) -proven effectiveness	None stated	-priority-setting not to be based on "blanket exclusion" -no statement of essential or core services provided by National Health Service -RHAs responsible for assessing health needs and, in turn, priorities

Table R1a. Summary of papers describing actual national/state-level priority-setting approaches by country/state continued

Author	Year published	Description of Priority-Setting Approach: Priority-setting committee and/or other individuals involved	Process used to set/identify priorities	Data collection instruments/ tools used	Principles/ factors considered	Final priorities identified	Conclusions/ outcomes
United States of America (Oregon)							
Blumstein Ham Ham Kitzhaber	1997 1997 1995 1993	*Priority-setting committee:* Health Services Commission (appointed by Governor of Oregon to develop prioritized list) comprised of 5 primary care physicians, one public health nurse, one social worker, and 4 members of the public *Other individuals involved:* -physicians -professional societies -public	*Formal* Oregon experiment comprised of 4 plans (iterations): Plan 1 1. Created list of 709 condition-treatment (CT) pairs and, through physician panels, assessed likely incremental medical benefit from treatment and net benefit of treatment weighted Quality-of Well-Being Scale used 2. Calculated cost-benefit ratio for each CT pair 3. Prioritized pair according to cost-benefit ratio Plan 2 1. 17 service categories created – each C-T pair placed into one category 2. Held public meetings and hearings state-wide to identify public values 3. Grouped public values into 3 attributes: value to society and to individual at risk and essential to basic health care 3. Prioritized 17 categories based on public values 4. Categories divided into 3 groups: (1) essential, (2) very important, and (3) valuable to certain individuals 5. Ranked CT pairs in each category based on net benefit 6. Adjusted rankings upon considering social factors, including public values Plan 3 Shortened CT pair list to 688 -eliminated Q-of-L as treatment outcome, as well as public's views Plan 4 Revised list following removal of factor regarding treatment leading to return to asymptomatic state	Plan 1: *Quality-of-Well-Being Scale* -includes 24 health or functional states and compares QWB with and without treatment Net Benefit of Service = QWB_{Rx} - QWB_{No} *Weighting process:* telephone survey of public Asked respondents to compare health states described by interviewer to death (Score 0) or perfect health (Score 1)	*Principles:* -equity **not** identified *Factors* Plan 1 -cost/benefit -quality-of-life Plan 2 -public health impact -treatment –related costs -public's views Plan 3 -probability of death -probability of returning to asymptomatic state -cost of avoiding death -removed quality -of- life -removed public values Plan 4 -removed factor 2	Criterion accepted for prioritizing CT pairs -ability of treatment to prevent death -average cost of treatment used as tie-breaker criterion	-priority-setting process made open and accountable to public -top 565 of 696 services on list received funding -reasons for deeming cost-effectiveness approach politically unacceptable -did not take into consideration "Rule of Rescue" principle -too many gaps in data -produced anomalous results

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	Process used to set priorities	Description of data collection instruments/ tools used	Principles /factors considered	Final priorities identified	Conclusions/ outcomes
Canada								
Mitton & Donaldson	2002	3 Regional Health Authorities in Alberta	*Priority-setting committee* -senior personnel within RHAs	*Informal* 1. Key issues raised by administrators to vice-presidents 2. Vice presidents discuss issues with senior executive 3. Board ensures priorities coincide with broad RHA direction 4. Priorities identified based on historical trends, demographic forecasting, and "crises" that arise	None stated	Factors -service utilization -cost -current service activity levels -need -urgency -political pressure -strategic direction/business plan -population health status	None stated	-identified need for systematic, explicit budget allocation (priority-setting) method
Sweden								
Swedish Government Official Report	1995	County of Dalarna (Sweden)	*Priority-setting committee* Self-appointed group comprised of heads of hospital departments and health centres, as well as county health service administrators	*Formal* 1. Attempted to devise system for classifying medical activities 2. Formulated priorities to be applied across health centre/departmental boundaries 3. Developed ranking list of 7 main groups to which patient's care can be referred (Falun model)	None stated	*Principles* -equity -fairness Factors -accessibility of care -patient factors (diagnoses or symptoms, mental state, and social situation)	Identified main basis for priorities: effect of illness on patient's life (i.e., consequences, according to medical expertise, of not providing or delaying care) Identified basis for prioritizing preventive activities -proven effectiveness -feasibility -risk of negative side-effects	-7 groups established to serve as a basis for waiting list prioritization (details not stated)
Swedish Government Official Report	1995	County of Gavleborg (Sweden)	*Priority-setting committee* Ethical committee with County Council	*Formal* 1. Prepared draft discussion document and circulated it to stakeholders	None stated	*Principles* -fairness -autonomy -"doing good" -avoiding injury and suffering *Factors* -consequences for others besides individual most affected Not to be considered -age -self-infliction of problem	-proposed 4-level priority classification based on gravity of disease/condition and benefit of "caring inputs"	None stated

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
Sweden continued								
Swedish Government Official Report	1995	County of Vasterbotten	*Priority-setting committee* Management within county health authority	*Formal* 1 Established prioritization principles 2 Identified factors that should be rejected when attempting to establish priorities 3 Applied principles of prioritization to both established and new treatment methods	None stated	*Principles* -universal entitlement to basic health care *Factors* Not to be considered -age -lifestyle -whether treatment method has been established -geographical justice	Identified 4 principles of prioritization for guiding decision-making (ranked) 1 Gravity – highest priority to states of infinite suffering or immediate threat to life 2 Disadvantaged groups higher priority than privileged ones 3 Cost-efficiency of input 4 Documented benefit of intervention	-recognized need to remove some covered services to make room for new ones removal to be based on ethical, medical, or economic assessments with priority given to first two
Switzerland								
Schopper et al	2000	Geneva	*Other individuals involved* - 5 stakeholder panels 1 Political all political leaders involved in health and social support issues 2 Institutional directors of medical and social institutions 3 Ambulatory medical and paramedical professionals fro private practice 4 NGO managers of health-related non-government organizations 5 Community leaders of community groups with no direct involvement in health	*Formal* Triangulated results of 3 complementary approaches 1 Ranked conditions according to potential years of life lost (PYLL) 2 Ranked conditions according to disability-adjusted years of life lost (DALY) 3 Delphi survey -5 stakeholder panels 4 Compared results from all three approaches 5 Included health problems identified as priorities by all 3 methods in priorities list 6 Added health priorities identified by both the DALY and Delphi method to list 7 Added main social determinants consistently identified by both professionals and lay public in Delphi survey	*Delphi questionnaire:* For first round -asked panelists to identify 10 most important health determinants and disease-oriented problems from a list of 20 determinants and 43 problem For second round -asked panelists to choose 5 determinants and 10 problems from list of 12 determinants and 10 problems, which at least 70% of panelists had chosen during the first round, and give a priority score to each one	*Factors* -frequency of problem -severity of problem/ condition -socio-economic impact of problem -effectiveness of interventions	Identified final list of priorities for Geneva 1 Depression 2 Cardiovascular disease 3 AIDS 4 Breast cancer 5 Chronic back pain 6 Violence in the family 7 Suicide 8 Unintentional injuries 9 Alcohol abuse 10 Tobacco abuse 11 Unemployment 12 Social exclusion	-Delphi method provided broadest view on health - findings from DALY and PYLL analyses may help to support those from the Delphi method -proposed a mix of qualitative and quantitative approaches to identifying priorities

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	**Process used to set priorities**	**Description of data collection instruments/ tools used**	**Principles/factors considered**	**Priorities identified**	**Conclusions/ outcomes**
United Kingdom								
Ham	1993	6 health districts (regional health authorities)	*Priority-setting committee:* Management within regional health authorities 1. City and Hackney (C&A) 2. Mid Essex (ME) 3. Oxfordshire (O) 4. Soilhull (S) 5. Southampton and South West Hampshire (SH) 6. Wandsworth (W)	*Formal* (details not stated) -health authorities employed variety of tools to help determine relative priority of different services	ME: 16 health care building blocks device C&A: 2-stage scoring method Stage 1 – bids ranked according to needs assessment Stage 2 – short-listed bids ranked on implementability, promotion of equity, effectiveness, integration with primary care, priority according to community health council, priority according to general practitioners, and other sources of funding W: Proposals scored (out of 100) and ranked using criteria -potential for health gain, improves quality of service, accords with local views, achievable in current year, and accords with national and regional priorities	-potential for health gain -potential to improve quality of service -findings from needs assessment -public's views -health professionals' views -accordance with governmental priorities	-results from each health district not stated	-availability of cost-effectiveness information is limited -lacking information on best practice to enable health authorities to select appropriate and effective services -appropriate ways of involving public in decision-making need to be established
Hope	2001	Oxfordshire Health Authority (United Kingdom)	*Priority-setting committee:* Priorities Forum (appointed by management within health authority to advise resource allocation decision-making) comprised of 30 members -general practitioners -hospital medical directors -health authority staff -hospital doctors -lay members	*Formal* 1. Developed ethical, priority-setting framework 2. Developed decision-making approach 1) Gathered evidence of cost/QALY or cost/year of life saved 2) Compared with guide cost 3) If proposed treatment < guide cost, recommend for funding; if proposed treatment > guide cost, asked "Are there grounds for paying more?", and, if yes, "Can that much more be justified?"	None stated	*Principles* -Rule of rescue	Identified priorities within ethical framework 1. cost effectiveness 2. equity 3. patient choice	-committee decisions have formed "case law" guiding future decisions -approach enabled health authority staff to make decisions without assembling priorities forum (i.e., committee)

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
United Kingdom continued								
Scott & Lees	2001	Argyll and Clyde Health Authority	*Priority-setting committee* Management within regional health authority *Other individuals involved* Stakeholder (multidisciplinary) panels: -Local Health Council -NHS managers -NHS clinicians	*Formal* 1. Reviewed priority-setting methods used in other UK health authorities 2. Selected attributes from those revised 3. Gathered opinions from stakeholder panels regarding factors to be considered when choosing between interventions 4. Nine utility criteria identified and weighted with maximum and minimum scores = Prioritization Scoring Index (PSI) 5. Descriptors devised to present potential outcomes for each criterion 6. Panel members used descriptors to score bids 7. Ranked interventions by average score for utility criteria and cost per additional person 8. Averaged two rankings to produce overall PSI rank	PSI -consists of "basket" of utility criteria, taking into account number of people to receive proposed intervention and marginal cost	*Factors* -benefit or utility -number of people requiring intervention -cost per additional person -considered in utility criteria: -potential health gain -prevention of ill health -quality of life -equity of access -addresses health status inequities -expressed demand -appropriateness -strength of evidence -known priority	-used PSI to rank 200 bids submitted to RHA (results/ priorities not stated)	-approach allowed for explicit prioritization of "bids" -approach could be applied across health programs as well as within them
New	1996	West Glamorgan Health Authority (United Kingdom)	*Priority-setting committee:* Local Ethics Committee (appointed by health authority) comprised of members with philosophy, public health, dentistry, law, health service management, and community health council backgrounds	*Formal* 1. Systematically reviewed technical and moral aspects of Authority's spending plans 2. Provided Advice to health authority which, in turn, was responsible for making final decisions	None stated	*Factors* -public's views -cost-effectiveness	None stated	None stated

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
United Kingdom continued								
Madden	1995	North Mersey Health Authority (United Kingdom)	*Priority Setting Committee* North Mersey Health Agency (formed from 3 Family Health Services Authorities and 4 district health authorities	*Formal* Priority-setting based on Programme Budgeting and Marginal Analysis (PBMA) 1 Held workshop to introduce staff to PBMA Step 1 formed 2 working groups 1 disease-based and 1 service-based Step 2 established structure of sub-programmes Step 3 Produced budget for sub-programmes Step 4 Produced wish list 2 Discussed wish list with stakeholder groups	PBMA overview 1 Group services into broad programmes 2 Identify sub-programmes 3 Identify service outputs and outcomes within sub-programmes and identify current budgets 4 Develop incremental and decremental wish list 5 Cost wish lists 6 Examine relative benefits of changes in spending 7 Consider impact of such changes on equity 8 Choose how to reallocate resource	*Factors* Quality-of-life Cost-utility	None mentioned	-PBMA found to be difficult to apply due to limited availability of data and quality -requires value judgments
Twaddle & Walker	1995	Glasgow (United Kingdom)	*Priority-setting committee* Greater Glasgow Health Board	*Formal* Process based on PBMA framework 1 Established working groups for service topics Each group 2 Identified objectives for service topic 3 Analyzed current spending and activity patterns by means of a programme budget 4 Identified margins reflecting perceived current deficiencies 5 Performed economic evaluation to asses cost and benefits of each marginal change (used evidence and experience) 6 Recommendations developed and presented to Public Health Director	PBMA described above	*Factors* -effectiveness of intervention -efficiency - need	None stated	-set purchasing or priority-setting within context of fixed budget - assembly of accurate programme budget was difficult for some services

Table R1b. Summary of papers describing actual regional health authority-level priority-setting approaches by country/province continued

Author	Year published	RHA	Description of Priority-Setting Approach					
			Priority-setting committee and/or other individuals involved	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
United States of America								
Kears & Lum	1992	Alameda County, California	Priority-setting committee County Board of Supervisors for Alameda County Health Care Services Agency asked to develop agency-wide process for prioritizing services Other individuals involved Focus groups -prominent health care advocates -clinicians -administrators Executive group -one representative from each focus group -director of Health Care Services Agency -3 members selected by agency director	*Formal* 1 Assembled 5 10-member focus groups representing service areas 2 Focus groups met twice to list health care needs, outline services currently provided, identify needs not met, and prioritize health services 3 Each group drafted individual reports to present to executive group 4 Executive group reviewed findings, addressed issues not dealt with by focus groups, and prepared integrated report 5 Presented report to Board of Supervisors 6 Scheduled public hearings to present findings	None stated	Principles -equity Factors -economic, social, and quality-of-life consequences of not providing care -width of gaps in service relative to need -individual needs	Identified priority groups based on unmet needs (ranked in order of priority) 1 High risk obstetric patients 2. Minority populations 3 High-risk youth and children 4 Isolated and frail elderly 5 Minority AIDS patients	-focus groups could not reach consensus on prioritized list of services -attempt to develop explicit set of priorities failed -from the outset, consensus among focus group members regarding need for rationing not established

Table R1c. Summary of papers describing hypothetical priority-setting approaches by country/province

Author	Year published	Setting	Description of Priority-Setting Approach					
			Priority-setting project participants	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
Canada								
Mitton et al	2001	2 Regional Health Authorities in Alberta	Senior executives within regional health authorities	1. Two programme areas were defined in each RHA 2. Programme budgeting approach based on retrospective analysis of existing databases accessible to RHAs was outlined 3. Split health regions into sub- regions and calculated overall spending compared to health status (measured by potential years of life lost (PYLL) 4. Identified sub-regions with lowest PYLL and highest spending per individual as those from which resources could be shifted to "worse-off areas"	PBMA overview: 1. Group services into broad programmes 2. Identify sub-programmes 3. Identify service outputs and outcomes within sub-programmes and identify current budgets 4. Develop incremental and decremental wish list 5. Cost wish lists 6. Examine relative benefits of changes in spending 7. Consider impact of such changes on equity 8. Choose how to reallocate resource	*Principles* -equity -fairness *Factors* -effectiveness -efficiency	None stated	-approach allows resource use to be compared in different ways (e.g., geographically or demographically) -current data available to regions considered adequate for estimating programme budgets -allows decision-makers to ensure fairness of resource allocation within region
United Kingdom								
Allen et al	1989	North Western Regional Health Authority	District health authorities submitting annual plans, which include bids for regional specialty development funds, to RHA for funding	1. District health authorities asked to provide additional data in bids to allow Quality-Adjusted-Life-Years (QALYs) to be calculated -nature of development -number of patients to be treated and cost -effectiveness of services in improving quality of life -life expectancy -patient characteristics 2. RHA calculated QALY per £1000 expenditure 3. Ranked those bids for which it was possible to calculate QALY	None stated	*Factors* -number of patients affected -effectiveness of intervention -patient characteristics -quality-of-life -need	Not explicitly stated – however life-saving treatments (e.g., pace-makers, angioplastics, and intensive care for children and babies) ranked highest; life-saving, but expensive treatments (e.g., open heart search) ranked in the middle; life-saving but continuous interventions (e.g., renal dialysis) ranked lowest	-approach made priority-setting more systematic -results sensitive to how outcomes are measured -cannot be used to assess certain bids for which outcome data would not be available -diagnostic services -new service developments -"ill-defined" proposal

Table R1c. Summary of papers describing hypothetical priority-setting approaches by country/province continued

Author	Year published	Setting	Description of Priority-Setting Approach					
			Priority-setting project participants	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
United Kingdom								
Farrar et al	1999	-Scotland	-members of Trust Medical Advisory Committee deciding which clinical service developments to fund, given a limited budget	1. Members of TMAC developed matrix for identifying characteristics that may make clinical service development attractive 2. Selected 5 most important dimensions (factors) to deciding whether a service should be funded 3. Assigned levels to key dimensions 4. Hypothetical scenarios combining different levels of dimensions were identified 5. Questionnaires containing 16 hypothetical scenarios were sent to 216 consultant working within hospital Trust -contained discrete choice questions 6. Regression analysis was used to establish relative importance of dimensions 7. Clinical directors scored their proposals according to how well they performed on each dimension and provided cost data 8. Scores were weighted using coefficients from regression analysis and then summed to give total weighted utility score for each proposal	Discrete Choice Modelling -stated preference technique for valuing patient benefits from health care services -asks respondents to make choices between different scenarios, trading –off one characteristic for another	*Factors* -level of evidence of clinical effectiveness -size of health gain -contribution to professional development -contribution to education or research -local and/or national priority	Identified 2 characteristics with most influence (i.e., of greatest priority to decision-makers): 1. evidence of clinical effectiveness 2. Health gain -ranking of specific development proposals not provided	-participant found questionnaire difficult to complete -techniques not considered to be practical
Posnett & Street	1996	RHA (anonymous)	-purchasers within RHA -disease-based expert working group	1. Identified one disease area 2. Expert group developed decision tree/flow diagram approach to identifying options for evaluation during marginal analysis of PBMA 3. Group suggested data sources for assessing decision points in flow diagram 3. Spread sheet model developed to simulate effects of change 4. Marginal cost per life-year saved calculated for all decision points	PBMA	None stated	None stated	-proposed approach to identifying options during PBMA ensures all possible relevant ones are identified and, in turn, considered ahead of time -removes bias introduced when expert group selects options

Table R1c. Summary of papers describing hypothetical priority-setting approaches by country/province continued

Author	Year published	Setting	Description of Priority-Setting Approach					
			Priority-setting project participants	Process used to set priorities	Description of data collection instruments/ tools used	Principles/factors considered	Priorities identified	Conclusions/ outcomes
United Kingdom continued								
Charlton et al	1981	Kent	-all professional and lay policy makers -professional advisory committee -district management teams -community health councils	1. Identified 7 major health service categories for obtaining judgments of priorities 2. Divided each category into sub-components 3. Conducted 3-round Delphi study: -information showing median changes preferred by each professional group fed back to respondents after each round -respondents revised opinions in light of other group's responses -respondents with outlying values given opportunity to explain their responses in open-ended questions	Delphi questionnaire -asked respondents to estimate relative importance of service categories - made 5 judgments: 1) Revenue allocation to major service areas 2) Revenue allocation to service areas with major categories 3) Allocation of extra monies between capital and revenue expenditure 4) Allocation of substantial revenue increases among major services 5) Allocation of substantial revenue reduction among major services	None stated	Priorities identified if additional revenues were available: -community services -children's services Priorities identified if expenditures were reduced: -acute care services to cut: -maternity -community care -children's services -services for mentally handicapped	-approach provided methods of obtaining quantitative estimates of relative funding priorities involving all stakeholder groups -respondents found methods to be effective in highlighting complexities of priority-setting within tight budgets
United States of America								
Vilnius & Dandoy	1990	Utah	-none directly involved -approach based on existing data	1. Applied BPR to four problems AIDS, motor vehicle injuries, coronary heart disease, and smoking 2. Determined size of problem using incidence/prevalence rates and scoring relative rate ranges out of 10 3. Determined seriousness of problem by examining urgency, severity, economic loss, and impact on others using decision-making group (scored out of 20) 4. Determined effectiveness from review of literature -ranked interventions on % basis and then converted value to score out of 10 5. Miscellaneous items scored on yes or no basis 6. Scores for each problem were totaled 7. Problems ranked on scores	Basic Priority Rating (BPR) overview: -applies defined problem to set of criteria which rate size (A) and seriousness (B) of problem, effectiveness of intervention (C), and a reality test of miscellaneous items (D) (propriety, economics, acceptability, and legality) -produces quantifiable value for each problem BPR formula: [(A+B) C]/ 3D = BPR	*Factors* -societal impact of problem -effectiveness of intervention -cost -acceptability to community -resource availability -legality	Identified priority of problems considered (ranked) 1. Smoking 2. Motor vehicle injuries 3. Coronary heart disease 4. AIDS	-BPR deemed valid tool, but sensitive to precision of data used -requires information that may be difficult to retrieve -allows for explicit identification of most critical issues or problems requiring interventions

Table R1d. Summary of papers describing conceptual priority-setting approaches

Author	Country	Description of priority-setting approach			
		Level of decision-making	Priority-setting factors Considered	Method/process proposed	Potential issues
Birch et al (1993)	Canada	Federal, provincial government	Population-based health care needs, equity	1. Allocate resources per capita on a population-wide basis 2. Adjust for community-specific demographics. 3. Adjust for community-specific health risks. 4. Adjust for community-specific relative costs.	1. Scope of program (eg all services or public health services only?) 2. Determining adjustment factors (relative needs) 3. Problems with having to change current funding levels. 4. Management issues. 5. Provider/consumer issues eg "cap" on provider payments, restriction of access to care.
Donaldson (1995)	UK	Health care program	Current activity levels and expenditures	1. Define the specific "program" (disease or service-specific). 2. Define the budget for the program – activities and expenditures (program budgeting PB) 3. Select services to be enhanced/reduced. 4. Compare the candidate services – costs and benefits (marginal analysis MA)	1. Takes time. 2. Multi-disciplinary – potential problem of "who is responsible?". 3. Data and information issues. 4. Some potential changes identified might be too broad.
Goold (1996)	USA	Community or organization	Not specified	Creation of a "Benefit Review Board", with 15 to 20 representatives of existing socially rooted organizations in health-related areas, with expert consultants used as needed. Decisions to be open. Best suited for concrete policy decisions eg establishing a benefit list.	1. Oversight. 2. Ensuring members are always aware of finiteness of resources ie dealing with the fact that increasing in some area would mean deleting or reducing in other areas.
Lomas (1997)	Canada	Societal	Effectiveness, public's views	A representative group of 10 to 20 individuals (representative of the general public if decisions on broad service categories are being made, or of a spectrum of patients if rationing via sociodemographic factors is being considered), preferably paid for participation. The group should meet routinely, and make decisions by consensus, not by aggregation of individual views.	This is only a "best guess", based on existing literature. Evaluation should be an inherent part of the proposed process.

Table R1d. Summary of papers describing conceptual priority-setting approaches

Author	Country	Description of priority-setting approach			
		Level of decision-making	*Priority-setting factors* Considered	Method/process proposed	Potential issues
Macdonald (1998)	Canada	Integrated health care delivery systems	Not specified	11 step generic process 1. Describe the facts 2. Identify issues, problems and gaps 3. Ensure all stakeholders are involved 4. Describe values and assumptions 5. Identify all resources available 6. Define options and costs 7. Prioritize options 8. Select a solution 9. Engage in public discussion 10. Make it work 11. Monitor and review	Not specified
Nord et al (1999)	USA	Societal	Health utilities, severity of condition, potential for health improvement	Modify utility gains by adjusting for severity of condition and the potential for improvement in health, based on a multiplicative model. Adjustments to be obtained from surveys.	1. Problems with measurement of the adjustment factors. 2. Relevant only to spending of resources on different patient groups, not to alternative ways of spending a given amount on a patient or patient group.
Shiell et al (2002)	Canada	Federal	Community-based agreement on principles for rationing, good evidence on costs and effects of investments in health services	1. Define a health services constitution/charter for Canada, based on community values 2. Strengthen the evidence base for the costs and effects of investing in health care 3. Use an economic analysis such as PBMA 4. Develop an incentive and institutional structure to ensure priority-setting decisions are implemented	1. This does not specify how much total spending on health care should be 2. Economic evaluation techniques are not sufficiently well-developed 3. PBMA still requires work to improve it 4. Difficulty in dealing with the decision to cut some service as a result of this approach 5. This approach may not be suitable across the entire spectrum of health services; there may have to be priorities set among different types of programs to begin with 6. Does not say much about this can best be implemented

Table R1e. Studies using a ranking method

Author(s)	Country	Method	Sample population	Setting	Results
Barkdoll (1983)	USA	Mail questionnaire	Representatives of 16 organizations in 1976, 61 in 1977	Country	There was a strong relationship between participant votes and decisions, "although a cause and effect cannot be absolutely determined"
Bowling (1996)	United Kingdom	Interview	2005 individuals 16 years or older	Country	12 health services were ranked. Highest rank to treatments for children with life-threatening diseases, next to special care and pain relief for the dying, and lowest rank to treatments fore fertility and for people 75 or over with life threatening diseases.
Bowling et al (1993)	United Kingdom	Mail questionnaire	350 members of a community group, 454 general public and 219 doctors	District	The public ranked life savings technologies as high (cf community services and mental health services), in contrast to the doctors; health education and family planning were ranked as low by the public, GPs and specialists, in contrast to public health doctors.
Furnham (1996)	United Kingdom	Questionnaire	101 volunteers	County	Non-smokers favoured over smokers, poorer people over the rich; females over the males, and "left-wing" over the "right-wing"
Hopton (1995)	United Kingdom	Mail questionnaire	3478 individuals, 16 and over	Region	Rankings of primary care services depended on the average health status of the respondent groups.
Lees et al (2002)	United Kingdom	Mail questionnaire	357 doctors; 1004 general public	Health region	Greater importance should be placed on services that improve health or QOL or prevents ill health; less on cost and govt. and health board priorities.
Schwartz et al (1999)	United Kingdom	Group discussion	Medical GPs, and clinic staff	Classroom	There were significant differences in the way student groups prioritized candidates for infertility treatment; there was less variation in the professional group, but they did not make decisions necessarily to maximize benefit or success rate.

Table R1f. Studies using rating methods

Author(s)	Country	Method	Sample population	Setting	Results
Anell et al (1997)	Sweden	Mail questionnaire	1360 individuals 18 and over	4 counties	Health services preferences are similar in many ways, but there are differences depending on age and education.
Baker et al (2001)	United Kingdom	Interview	462 patients and 1040 general public, over 18.	City	Treatment of emergency and life-threatening conditions is an absolute priority; there is also support for conditions which are treatable and seriously affect QOL.
Fowler et al (1994)	USA	Telephone interview	206 adults and 44 "Fortune 500" benefit plan executives	Country	Rankings correlated with seriousness of the patient's condition and likely efficacy of the services. The public gave a higher ranking to long-term care and services to relieve worry higher than benefits officers, but lower for services for conditions in for which the patient could be seen as at fault (ie substance abuse)
Hadorn (1991)	USA	Telephone interview	1000 individuals	State	List of reductions of QOL due to various clinical conditions was generated.
Israeli et al (1999)	Israel	Questionnaire	Members of the public	Country	There are differences in rankings across population subgroups
Pickard et al (2001)	United Kingdom	Interviews, mail questionnaires	56 lay members of Primary Care Groups.	Country	Lay members view their role in board decision-making to be peripheral.
Rosen et al (2001)	Sweden	Questionnaire	1574 patients, 18 and over	Region	There were significant differences between respondent age groups in free choice of primary physicians, and in whether they have enough information to make the choice.
Ryynanen et al (1999)	Finland	Mail questionnaire	667 nurses, 803 doctors, 1096 politicians and 1156 general public	Country	Highest ranked criteria were age (children and the elderly), severity of the disease and its prognosis. Increasing treatment fees and restricting expensive treatments were the most acceptable methods for restricting services.
Shmueli (2000)	Israel	Interviews	2030 Jewish persons	Country	The 3 most preferred prioritization criteria were chances of recovery, number of dependents and young age.
Ubel et al (1996)	USA	Two questionnaires	53 students	Classroom	There is a discrepancy between preferences based on people's utility scores and their explicit rationing choices

Table R1g. Choice-based studies

Author(s)	Country	Method	Sample population	Setting	Results
Charny et al (1989)	United Kingdom	Interviews	719 individuals	City	The public consider lives to be of unequal worth; a very siginificant proportion of participants found it impossible to make choices between individuals for a service.
Pinto Prades (1997)	Spain	Interviews	30 students	Classroom	At the aggregate level, the Person Trade Off technique is slightly better than Standard Gamble and much better than the Visual Analogue Scale for determining health state utilities.
Ryynanen et al (1996)	Finland	Questionnaire	49 general public and 140 students	Classroom	Children and patients with severe disease were ranked high, but the elderly, patients with a mild disease, and those with a "self-acquired" disease were ranked low.
Schwappach (2002)	Germany	Interactive web survey	129 general public	Unspecified	Participants strongly preferred to improve patients' health rather than avoiding decline.
Shmueli (1999)	Israel	Interviews	2006 individuals	Country	The "Rule of Rescue" is dominant for more tha a quarter of the respondents even if it postpones death for only a month; Prioritization by lottery was acceptable to more than 10%; economic condition, gender and health status had no effect on choices, but age and religiousness did.
Ubel (1999a)	USA	Questionnaire	479 prospective jurors	City	Majority supported dividing resources evenly between a group of moderately ill patients and one of severely ill patients; preference ranking for severely ill patients depended on relatively minor changes in wording in the questionnaire.
Ubel et al (2000)	USA	Questionnaire	495 prospective jurors and 1294 physicians	City	A majority of respondents favoured 100% coverage of a less effective test rather than 50% coverage of a more effective and expensive test; but when the choice was between 50% coverage for the poorer test and 25% for the better one, only about a quarter of respondents favoured it. Preference for equity over efficiency is not always maintained.
Ubel et al (2001)	USA	Questionnaire	68 prospective jurors	City	People's preference for equity over efficiency is not absolute, and depends on how questions are framed, and the order in which they are asked.
Vetter (1989)	United Kingdom	Questionnaire	719 individuals	City	The clearest consensus was that younger people should have preference over older people and that married people should have preference over single people. It was harder to choose between other types of subgroups.

Author(s)	Country	Method	Sample population	Setting	Results
Dicker et al (1995)	United Kingdom	Interviews	16 patients	City	It was not accepted that prioritization was necessary; it was felt that the task was difficult; that doctors should act as advocates for patients; there was no faith in politicians' views on priorities; there was bias against age as a priority; the principle of equity was supported.
Donaldson et al (1997)	United Kingdom	Interviews	82 parents	Health region	WTP data seems to have the potential to provide health care purchasers and providers with information on intensity and direction of consumer preferences for narrow health acre options.
Nord et al (1995)	Australia	Mail questionnaire and interviews	551 general public (questionnaire) and a subset of 199 interviewed	City	The majority felt that cost should not be a major criterion in prioritization. Cost-effectiveness may be a simplistic approach to this.
Roberts et al (1999)	United Kingdom	Interviews	91 individuals	Unspecified	Many of the respondents did not choose between options in line with QALY maximization; however, QOL seemed to be a factor driving choices against QALY maximization; the level of QOL expected be achieved by treatment was viewed as important.
Schopper et al (2000)	Switzerland	Delphi panels	Varied from 293 to 165 in the second round	Canton	Cardiovascular and respiratory disease, breast cancer, AIDS, traffic injuries, chronic back pain, psychosocial disorders and substance abuse were identified as priorities; Delphi is a useful tool to reach consensus on health priorities.

Table R1h. Studies using individuals

Table R1i. Studies using groups

Author(s)	Country	Method	Sample population	Setting	Results
Bentley et al (1995)	USA	Town meetings	3 separate groups of 10 university staff, 12 faculty members and 8 students	University	The town meeting format may be useful for gathering information about values and health care reform. But this study did not produce any rankings of services.
Bowie et al (1995)	United Kingdom	Focus groups	8 panels (12 members of the public each)	Health region	Seems to be useful approach to obtain public's views; more weight is being assigned to these panel conclusions by the health authority. But no explicit ranking are provided in this paper.
Bradley et al (1999)	United Kingdom	Focus groups	24 groups selected from 4 GP practices and a school.	Region	The panels produced specific ideas for developing England's health strategy.
Cookson et al (1999)	United Kingdom	Focus groups	60 individuals	Region	Three broad rationing principles were suggested: "Rule of Rescue", health maximization and equalization of lifetime health.
Dolan et al (1999)	United Kingdom	Focus groups	60 individuals	Region	People's views on priorities change after discussion^; they become less likely to discriminate against people who indulge in behaviour that is risky to health.
Dolan et al (2000)	United Kingdom	Focus groups	60 individuals	Region	Initially, respondents favoured treating two groups of patients who differed only in terms of their respective gains in length or quality of life. Subsequently, they were prepared to trade this off for patients who stand to benefit most from the treatment..
Hope et al (199*)	United Kingdom	Priorities forum	Staff and physicians of the health authority	Health region	The forum has provided specific recommendation on individual services.
Kapiriri et al (2002)	Uganda	Focus group	57 community members	Subcounty	Problems as perceived by the community representatives were similar to those identified by the burden of illness study undertaken nationally. A nominal group technique could be useful for supplementing national data with local perspectives.
Kears et al (1992)	USA	Focus group	5 groups of 10 each selected by department heads, and an executive panel of 10.	County	None of the focus groups was able to reach consensus on how to prioritize services.
Lenaghan et al (1996)	United Kingdom	Citizens' jury	16 individuals	Health region	The Citizens;' jury process seems to be a useful way of getting individual views into the priority setting process. But this paper presented no specific results of a priority setting exercise.
Stronks et al (1997)	Netherlands	Panels	6 separate groups (about 9 individuals each) representing patients, the public, providers and insurers.	Unspecified	Providers thought most services were necessary; GPs preferred using health and financial need as criteria; specialists proposed increasing efficiency and preventing inappropriate utilization; the public preferred to exclude relatively inexpensive treatments; patients preferred to limit access to preventive and acute services.

Table R1j. Reviews

Author(s)	Country	Purpose	Conclusions
Burgoyne(1997)	United Kingdom	To describe and address how rationing was represented in media following a decision by the NHS on an individual patient	There were divergent views in the media; agreement is only at the most abstract and basic level – ie ideally, the principle of need should drive allocations; some saw priority-setting as inevitable, but there was little agreement on the criteria; some felt physicians alone should decide, others felt all interested parties should.
Dixon et al (1991)	USA	To discuss the Oregon approach to priority setting for consideration by the NHS	Some services in the NHS may be suitable for explicit rationing; Oregon's approach to reaching consensus on health issues may be applicable, but representative sampling must be assured; combining quality of life and public values might be challenging.
Edgar (2000)	New Zealand	To describe the work of the National Health Committee and its consultations with the public on priority setting for health services.	Various means of consultation have been employed, including consensus panels, public forums, focus groups, submissions etc. The public helped identify 6 service areas as being of high priority (e.g., children's services, hospice services); support was obtained for 4 criteria: benefit/effectiveness, value for money, fairness and consistency with community values; there is a clear agreement to be explicit about rationing.
Ham (1997)	Various	To review experiences with health care priority setting in various jurisdictions and draw out possible lessons	A variety of methods have been tried in; there is no simple or technical solution; explicit priority setting must be a continuous process; value judgments are important and will depend on the particular individuals and groups; so it important to draw on these explicit values.
Martin (1995)	USA	To review of 8 years of experience with the Oregon approach	Health care reform as attempted by the state of Oregon can work, but it is not easy or immediate; there are still challenges to the implementation, and required cost-containment processes.
McIver (1995)	United Kingdom	To consider the types of information that the public might need for priority-setting, and to review three studies done in the country.	Three suggestions on involving users (the public): involving them from the beginning; ensuring that they and professionals are briefed equally; giving both groups equal weight at meetings; making sure both groups are kept informed of progress.
Mossialos et al (1999)	Various	To describe earlier studies, and discuss the issues related to public involvement in rationing and priority-setting.	Attitudes to priority-setting vary across Europe. But 30% to 50% of the public support priority-setting when funding is limited; in countries where the public has been exposed to issues of rationing and priority setting, there is more familiarity and support for these; acceptance of rationing is more likely to be expressed with increased education; importantly, people do not consider their own self-interests above community ones when making choices; there is also strong belief that priority-setting decisions be the responsibility of the medical profession; waiting time for treatment was consistently the top choice for the bases on which priority setting should take place; there is strong support for methodologies for obtaining public input which is both informing and deliberative.
Renn et al (1993)	Germany, USA	To describe citizens' panel approaches in non-health care situations.	Citizens' panels have been used in Germany for urban planning and to consider energy policies; recommendations were made about nuclear energy policy; the reaction has been mixed, and the role of the panels in formulating recommendations has been questioned; however, it was agreed that it is a good way to elicit preferences and educated responses of citizens in a short period of time. A smaller scale project on sewage sludge management was conducted in the US, and the recommendation of the citizens panel was accepted and acted on by the proponent of the proposed project.
Richardson et al (1996)	United Kingdom	To discuss how community involvement might take place in health care rationing, based on a case study in the UK	There were different perspectives in the case study, including the health authority, the father of the patient, the community and the media. In general, there will be multiple perspectives in rationing discussions. Though there should be public scrutiny of health resource allocation, decisions on treating a single patient should not be. There is a role for community involvement, but there is no easy solution.

Table R1k. Conceptual/discussion pieces

Author(s)	Country	Purpose	Conclusions
Charles et al (1993)	Canada	To present an analytic framework for lay participation in health care decision-making based on decision-making domains, role perspectives and levels of participation.	More attention should be paid to specifying the goals of lay participation and evaluating the results; providing the public with technical information to facilitate decision-making is important; a key policy challenge is to identify the specific relevant types of information. This framework could be used to reduce the potential for ambiguity in both advocating and interpreting recommendations arising from lay participation.
Coast (2001)	United Kingdom	To explore citizens' and their potential agents' preferences for an agent to make decisions on behalf of the citizen.	The 3 main factors that influence the desire for a citizen to use an agent to make societal rationing decisions are: knowledge, objectivity and the potential for distress resulting from being involved in the denial of care. Most agent informants (physicians, hospital administrators, etc) felt that citizens have neither sufficient knowledge nor objectivity to participate in decision-making
Cookson et al (2000)	United Kingdom	To review three principles of justice (need, maximizing and egalitarian principles) for priority setting.	In the academic literature, these principles are more narrowly focused than what appears to be supported by the general public; philosophers have yet to develop a coherent and more pluralistic theory that combines the three principles.
Daniels et al (1998)	USA	To argue that "accountability for reasonableness" is a fairer way to rationalize health care services compared to market accountability or regulation.	Accountability for reasonableness requires that (1) decisions and rationales be publicly accessible, (2) these rationales rest on evidence, principles, etc. that all fair-minded parties agree are relevant, (3) there is an appeal mechanism, with the capacity to reverse decisions, and (4) there is enforcement of the first three principles. Accountability for reasonableness empowers collaborative decision-making by physicians and patients decisions will no longer be in "black boxes"; it addresses problems of legitimacy and fairness.
Doyal (1998)	United Kingdom	To argue that public involvement has a limited role in health care rationing decisions.	Local majorities must not be have unlimited scope to decide on behalf of others; public consultations can be unduly influenced by the way in which questions are framed, who presents the options, and on individual characteristics of the participant; rules of representation, communication and debate regarding the principles for rationing are required; the right to access to appropriate health on the basis of equal need is a right that must be protected from collective or individual arbitrariness.
Giacomini (1999)	Various	To discuss how health technologies might be "assembled" prior to being compared in priority-setting exercises.	The process of assembling technologies for trade-off considerations is heavily values driven; boundaries involved in technology trade-offs move with jurisdictional budget structures, institutionalized interests, ideology, and information (e.g., evaluation data); the technology assembly process is as important as the technology assessment process; how the choices are set up to compare technologies will influence the decisions made.

Table R1k. Conceptual/discussion pieces

Author(s)	Country	Purpose	Conclusions
Hadorn	USA	To examine how people's preferences for outcomes of health care can form a coherent basis for explicit priority-setting	Priority setting rules cannot be based on individuals' preferences; "Preference for services" approaches have relatively little to offer to the allocation problem; "preference for outcomes" is better; generic (not disease-specific) outcomes are preferred, and they should be determined from pre-illness preferences of the entire population; individual preferences should be aggregated an appropriate measure.
Jacobson et al (1995)	United Kingdom	To review a study done earlier, and to discuss issues arising from that and other similar public consultations.	There are technical issues (representativeness of public response, sufficient numbers in subgroups, formulation of specific questions, lack of good effectiveness and cost-effectiveness information), ethical issues (insufficient sharing of information by health authorities and physicians with the public, relative weighting of conflicting values between the public and professionals, difficulty for individuals to represent community values, evidence that the public may not support the concept of equal treatment for equal need), and political issues raised by public consultation.
Jordan et al (1998)	United Kingdom	To describe methods used to consult with the public regarding health needs.	Quality of local consultation is still questionable; information gathered from consultation can be marginalized or incorporated depending on professional priorities; there are limitations to professional knowledge which consultation might help with; there is greater scope for public involvement in decision-making.
Lenaghan	United Kingdom	To review the Citizens' Jury as a means of incorporating the public's views in priority-setting	An independent evaluation has shown that citizens' jury is a useful tool, and has a number of strengths, including built-in mechanisms to ensure their views influence service decisions; given enough time and information, the public are willing and able to engage in priority-setting debates; the openness of the process is an asset, and enhances legitimacy, which is essential both to the public and professionals; still, there are numerous questions that need to be asked about this mechanism.
Lomas	Canada	To evaluate the potential roles of members of the in providing information to the priority-setting process.	Individuals play the role of taxpayer (what should be funded), patient (what (s)he wants to receive) and citizen (what the system will offer); the role of the public should be limited to providing input; they do not have the interest or skills to engage in priority-setting at the level of specific services; there is no best method for obtaining public input.; problems include lack of good information and lack of opportunity for informed discussion.
Mullen	United Kingdom	To provide an overview of different methods for eliciting values from the public.	Numerous methods exist, but the choice of method is not obvious. The factors to consider are whether to use a single or multiple attribute approach, whether to offer constrained or unconstrained choices, how to measure intensity of preference and aggregate individual responses, dealing with costs, and ease of use and transparency. A list of questions which might help in selecting a technique is provided.

Table R1k. Conceptual/discussion pieces

Author(s)	Country	Purpose	Conclusions
New (1997)	United Kingdom	To identify public values relevant to public health and to address ethical questions concerning public involvement in decision-making.	Seven public health values were identified: equity, compassion and altruism; security; efficiency; freedom and autonomy; democracy; health; there are arguments for and against public involvement; problems include the representativeness of participants, accountability, generalizability of decisions taken locally; whether people should be compelled to participate (to enhance representativeness). Especially if the influence of the public involvement becomes significant, value conflicts are obviously going to emerge.
Shackley et al (1995)	United Kingdom	To discuss consumer participation at two levels: (1) of deciding whether or not a service should introduced, or its scale changed, and (2) how best to introduce it.	The willingness to pay (WTP) approach may be useful for eliciting community values reflecting the intensity of preference; conjoint analysis is proposed as a method to help in deciding how a certain program will be implemented. These methods overcome some of the problems with other existing methods.
Schickle (1997)	United Kingdom	To discuss some of the ethical consequences of using empirical data on public preferences for priority setting.	Public preferences that have been reported in earlier studies all have ethical implications; simple rankings of services are inadequate, and the values underpinning the rankings need to be justified; there are also problems with aggregating preferences of individuals; there should be testing to see if groups who state preferences are willing to change health care provision in keeping with them and if they are willing to accept the ethical consequences of their choices.
Ubel (1999b)	Unspecified	To outline a preliminary research agenda combining values research with ethics, to identify and measure acceptable community values that are consistent across measurement methods.	A two pronged approach is proposed: first, looking at values as they are expressed across many measurement methods, to see if patterns emerge, and second, to examine the values to make sure they do not discriminate against vulnerable groups; community values which are measured should be "actionable" ie it should be possible to incorporate them into health care, one example is cost-effectiveness.

Eleven papers reported on studies in which **groups** were consulted (Table R1i). The most common method of eliciting values and opinions was the focus group, although citizens' juries, panels comprising members of health authorities, and town hall meetings were also used.

Reviews based on primary studies (**category (ii)**) outlined approaches used to engage the public during priority-setting exercises in several developed countries around the world and identified the pros and cons of do so (Table R1j). However, none compared the effectiveness of various approaches in different contexts. Moreover, many of the papers stated that no single "generic" approach exists, since selection of an approach depends upon local population-specific factors.

Category (iii) consisted of papers addressing concepts, issues and frameworks (Table R1k). Authors are not unanimous in their support for increased public participation. However, there appeared to be agreement on the need for public involvement at some level in order for health care systems to be considered accountable and legitimate. From these studies, it was concluded that even if the technical problems can be overcome, (e.g., the need for good and clear information to be available for citizens involved in these processes), questions of ethics and social values, which cannot be answered in a general sense, as well as political factors, will remain.

Legal cases

Twenty-seven Canadian cases in which reasons for judgment were either directly or tangentially related to health care resource allocation issues originated from 8 provinces (primarily British Columbia and Ontario). Their distribution according to highest court level hearing the cases was 3 by the Supreme Court of Canada, 8 by the Provincial Courts of Appeal, and 16 by Courts 'of first instance' or 'trial courts'(provincial Courts staffed by federally appointed trial judges).

Although the courts did not consider these cases specifically from the perspective of resource allocation decisions, they could be categorized (roughly) into four groups:

i) Litigation seeking declarations that depriving or restricting access to specific health services violated the Charter of Rights and Freedoms (n=6)
ii) Litigation seeking similar declarations in relation to laws regulating or restricting health professional activities or billing practices (n=6).
iii) Malpractice lawsuits where resource allocation issues were linked to the determination of legal standards of care (n=4).
iv) Applications for judicial review or judicial appeals of government decisions that would have restricted access to specific health services (e.g., abortion services outside hospitals) or eliminating/consolidating health facilities (n=6)
v) Other cases (n=5)

Of the cases in **category (i)**, 1 was a Supreme Court decision, 1 a Court of Appeal decision where leave to appeal to the Supreme Court was denied, 1 a Court of Appeal decision (likely to be appealed to the Supreme Court), and 3 were trial court decisions. In 4 of these cases, the Court explicitly referred to evidence presented to it, or indicated a desire for evidence on resource allocation issues to be presented. This was typically through expert opinion or representatives of government or government organizations. In 3 cases, no evidence was referenced, in 4, legal or ethical principles were referenced, and in 3, 'where do we go from here?' options were referenced. In all cases, the option to 'make the services available' was stated without specifying how it was to be accomplished with available resources.

(Cases cited: Auton v. British Columbia (Minister of Health); Brown v. British Columbia (Minister of Health); Cameron v Nova Scotia (Attorney General); Eldridge v. British Columbia (Attorney General); Ontario Nursing Home Association v. Ontario; Stein v. Quebec (Regie de l'Assurance-maladie)

Of the cases in **category (ii)**, 3 were Court of Appeal decisions, and 3 were trial court decisions. Four of these consisted of legal challenges to physician resource planning policies (e.g., making health care billing numbers contingent upon geographic allocation of physician services). In addition, no evidence on resource allocation was referred to in any of these cases except for general references to the objectives of the provincial health care insurance legislation. No 'go forward' policy options were identified in any of these cases other than to work within the existing legislative framework.

(Cases cited: Halvorsen v. British Columbia (Medical Services Commission); Mia v. Medical Services Commission for British Columbia; Rombaut v. New Brunswick (Minister of Health and Community Services); Tsang v. Delta Hospital ; Waldman v. British Columbia (Medical Services Commission); Wilson v. Medical Services Commission for British Columbia)

Of decisions pertaining to cases in **category (iii),** one was at the Court of Appeal level and the other 3 were at the trial court level. All cases involved allegations of clinical malpractice in situations where certain technical or human resources allegedly were unavailable at all or on a timely basis. The Courts' comments on resource allocation were tangential to the decision; nonetheless, some of the comments were strongly critical of the lack of such resources. Evidence on resource availability was exclusively anecdotal and delivered by defendant physicians and expert (physician) witnesses. Two cases decided in favour of the plaintiff, 2 in favour of the defendants.

(Cases cited: Law Estate v. Simice; McLean v. Carr Estate: Bateman v. Doiron; Baynham v. Robertson)

In **category (iv)** cases, 3 were Court of Appeal and 3 were trial court decisions. All but one related to decisions of the Ontario Health Services Restructuring Commission (HSRC). All cases focused on the question of whether the government or government delegate had the legal jurisdiction to make the decisions or rules they were purporting to make. Resource allocation issues were tangential to the reasons for decisions in all cases. With the exception of minority opinion comments in one case, none of these Courts referred explicitly to evidence on resource allocation issues. In all of the Ontario HSRC cases, the Courts explicitly deferred to whatever the Commission had decided and declined to review evidence to test the merits of those decisions. In no cases were ethical or legal principles of resource allocation referenced (although legal principles around the regulatory jurisdiction of governments were referenced).

(Cases cited: Doctors Hospital v. Ontario; Douglas v. Ontario; Lexogest Inc. v. Manitoba (Attorney General); Pembroke Civil Hospital v. Ontario; Russell v. Ontario (Health Services Restructuring Commission); Wellesley Central Hospital v. Ontario)

The 5 decisions in **category (v)** cases had no clear commonality. Two were Supreme Court decisions, 1 a Court of Appeal decision, and the remaining 3 were trial court decisions. In the 5, the legal challenge was:

1) to a damages award for future group home support of an injured child, on the basis that the publicly funded home care may no longer be available by the time the child reaches adult age
2) of a 'do not resuscitate' order

3) of the requirement that physicians cannot provide medical services concurrently in the public and private sectors
4) of a cap on health insurance benefits for treatment outside Canada

5) of a hospital regulation that effectively required physicians to retire from their medical staff at age 65 subject to demonstrating a skill not possessed by any other member of the medical staff

Of these decisions, in only one did the Court refer to evidence on resource allocation decisions (the mandatory retirement case in which the cost of a performance based assessment of physicians was referenced but not relied on). The resource allocation issue was tangential to the decision in all cases. Only the group home support case articulated a legal or ethical principle around resource allocation.

(Cases cited: Brown v. British Columbia (Attorney General); Chaoulli v. Quebec (Procureur-General); Krangle (Guardian ad litem of) v. Brisco; Sawatzky v. Riverview Health Centre Inc.; Stoffman v. Vancouver General Hospital)

In summary, case law on this subject was found to be very limited. Nonethless, several general characteristics emerged from this review. First, health care resource allocation decisions are increasingly being challenged in the Charter arena. Key questions of whether health service providers are governed by the Charter, and whether health services are protected under the Charter, are increasingly being decided in favour applying the Charter. The Auton case identified in the review, which was recently decided by the British Columbia Court of Appeal and will almost certainly be appealed to the Supreme Court of Canada, is expected to become an important marker of where the law is headed in this regard. Second, the health care resource allocation issue remains on the margins of malpractice litigation, despite the occasional loud and clear obiter judicial comment on the subject. Third, the evidence presented to Courts on resource allocation issues continues, as a general rule to be non-existent or, at best, sketchy and anecdotal. Fourth, although some Courts have commented on the importance of not sacrificing individual or group welfare for resource allocation reasons, they have yet to explicitly discuss the trade-offs associated with enforcing these entitlements. Fifth, although governments and their delegated bodies continue to be given wide latitude to make policy decisions around the restructuring of health services and health service delivery systems, Courts do not seem to be prepared to allow these decisions to go beyond what the government's own laws, and legal rules of fair process, permit.

2. Authors' Survey

Authors of papers on priority-setting processes
Authors of 27 papers responded to the survey by completing and returning questionnaires (response rate of 90%). To determine whether or not these papers (i.e., respondents) systematically differed from those for which no response was received (i.e., non-respondents), characteristics of papers comprising each group were compared (Table 2a). Two of the 3 non-respondents originated from countries represented by a single paper. Therefore, from the outset, sample size was extremely small. Although a significant majority, if not all, of the papers in each of the remaining "characteristic" sub-categories fell within the "respondents" group, the exclusion of 2, which resulted in the absence of representation from two countries, may affect the generalizability of the results.

Table R2a. Characteristics of priority-setting papers used to assemble the population of authors surveyed

Characteristic	Respondents N (%)	Non-respondents N (%)	Total N
• **Survey population size**	27 (90)	3 (10)	30
• **Type of paper**			
Description of actual priority-setting exercises	21 (88)	3 (12)	24
Description of hypothetical priority-setting projects	6 (100)	0 (0)	6
• **Publication year**			
Mean	1997	1995	---
Range	1992-2002	1993-1999	---
• **Country of origin**			
Austria	1 (100)	0 (0)	1
Canada	1 (100)	0 (0)	1
Finland	0 (0)	1 (100)	1
Germany	1 (100)	0 (0)	1
Israel	1 (100)	0 (0)	1
New Zealand	3 (75)	1 (25)	4
Norway	2 (100)	0 (0)	2
Spain	1 (100)	0 (0)	1
Sweden	4 (100)	0 (0)	4
Switzerland	1 (100)	0 (0)	1
United Kingdom	8 (100)	0 (0)	8
United States	4 (80)	1 (20)	5

Through a series of open-ended questions, each author was asked whether or not he/she knew of any decision-makers who were aware of his/her paper and, if yes, how he/she believed this awareness was gained. Approximately 89% responded positively (i.e., replied "yes"). Content analyses of statements describing how decision-makers became aware of papers resulted in the list of mechanisms displayed in Table 2b. Authors of over 80% of the papers indicated that decision-makers had participated in the project/exercise which formed the basis for the paper. In, general, "participation" meant taking part in priority-setting using the approach discussed in the paper. Thus, the point at which awareness was achieved occurred *prior to* completing the paper. In cases where this point occurred *after* completing the paper, approaches most commonly employed were both one author-initiated.

To assess the utility of published literature to decision-makers, authors were asked whether or not they knew of decision-makers who had not only become aware of their paper, but also used the information addressed within it. Approximately 83% (20/24) replied "yes". In addition, they provided brief descriptions of the manner(s) in which the information was used, as well as why they believed it was used (Table 2c). The majority of manners/ways presented suggested that the priority-setting approach addressed in the paper had become part of local decision-making processes. Reasons provided primarily related to decision-makers being involved in the project/exercise, themselves.

Authors of papers on elicitation of public values/opinion

Authors of 58 papers responded to the survey (response rate of 85%). Once again, to assess whether or not these papers (i.e., respondents) systematically differed from those for which no response was received (i.e., non-respondents), characteristics of papers comprising each group were compared (Table 2d). In general, a significant majority, if not all, of the papers in each "characteristic" sub-category fell with the "respondents" group. Therefore, this group was deemed representative of the population initially surveyed.

Table R2b. Summary of decision-makers' awareness of priority-setting paper

Mechanisms through which decision-makers became aware of paper	Respondents N (%)*
• Before paper completion (i.e., during completion of project addressed in paper)	
1. Project commissioned by decision-makers	4 (17)
2. Project committee/team included decision-makers	8 (33)
3. Project participants (i.e., study sample) included decision-makers	20 (83)
4. Informal discussions between author and his/her colleagues involved in decision-making	1 (4)
• After paper completion	
1. Author sent paper to decision-makers	9 (38)
2. Author contacted decision-maker(s) to discuss paper	10 (42)
3. Author presented paper at conference(s) attended by decision-makers	2 (8)
4. Author held seminar/workshop for decision-makers	4 (17)
5. Informal discussions between decision-makers involved in project and their colleagues	1 (4)
6. Paper published in journal(s)/document(s) read by decision-makers	3 (13)
7. Informal discussions between author and his/her colleagues involved in decision-making	2 (8)
8. Decision-makers' involvement in follow-up projects	2 (8)

*Percent based upon number of authors reporting that decision-makers were aware of his/her paper (n=24).
Note: Percentages do not total 100% since some authors provided more than one comment.

Table R2c. Summary of *how* and *why* decision-makers used priority-setting papers

Usefulness of papers to decision-makers	Respondents N (%)*
• Formed basis for program of research on priority-setting	1 (5)
• As a guide for implementing a priority-setting framework	3 (15)
• To develop priority-setting criteria/guidelines	3 (15)
• To revise current priority-setting criteria/guidelines	2 (10)
• Validate current priority-setting processes	1 (5)
• Formed basis for priority-setting exercises/processes	9 (45)
• Support current government policy/position	2 (10)
• Stimulate debate/discussion about current priority-setting policies	1 (5)
Reason(s) decision-makers used information in paper	
• Directly relevant to certain decision-makers	
1. Based on project initiated at decision-makers' request	10 (50)
2. Based on project conducted in decision-makers' jurisdiction	5 (25)
3. Based on project that was part of local planning	15 (75)
• Supported current government policy/position	6 (30)
• Provided systematic approach to priority-setting	3 (14)
• Provided practical as opposed to theoretical information	1 (5)
• Approach presented was simple and easily-understood	2 (10)

*Percent based upon number of authors reporting that decision-makers used his/her paper (n=20).
Note: Percentages do not total 100% since some authors provided more than one comment.

Table R2d. Characteristics of public involvement papers used to assemble the population of authors surveyed

Characteristic	Respondents N (%)	Non-respondents N (%)	Total N
• **Survey population size**	58 (85)	10 (15)	68
• **Type of paper**			
Reports of original data	38 (90)	4 (10)	42
Reviews of reports of original data	8 (80)	2 (10)	10
Conceptual/discussion pieces	12 (75)	4 (25)	16
• **Publication year**			
Mean	1997	1995	---
Range	1979-2002	1983-1999	---
• **Country of origin**			
United Kingdom	28 (82)	6 (18)	34
United States	13 (93)	1 (7)	14
Finland	3 (100)	0 (0)	3
Israel	3 (100)	0 (0)	3
Sweden	2 (100)	0 (0)	2
Australia	1 (100)	0 (0)	1
Canada	1 (33)	2 (67)	3
European Union	1 (100)	0 (0)	1
Germany	1 (50)	1 (50)	2
Netherlands	1 (100)	0 (0)	1
New Zealand	1 (100)	0 (0)	1
Spain	1 (100)	0 (0)	1
Switzerland	1 (100)	0 (0)	1
Uganda	1 (100)	0 (0)	1

Authors of half of the papers (n=29) reported knowing at least one decision-maker who was aware of his/her paper. Following content analysis of responses indicating how decision-makers became aware of papers, a list of mechanisms almost identical to that outlined for the priority-setting literature emerged (Table 2e). Authors of two thirds of the papers indicated that decision-makers had been involved in the work/project which formed the basis for the paper. The level of their involvement varied from commissioning the project to serving as an investigator. Thus, the point at which awareness was achieved most frequently, once again, occurred *prior to* completing the paper. Approaches found to be most common when the point of awareness occurred after completion of the paper included one author-initiated mechanism and one decision-maker-initiated mechanism (i.e., author sending decision-makers copies of the paper and decision-makers reading journals/documents in which the paper was published).

Authors of approximately 62% (18/29) indicated that the information presented in their paper had been used by decision-makers (Table 2f). Over half of the manners/ways in which it had been used related to the priority-setting process, itself, suggesting that public values/involvement

in priority-setting (the main topic of these papers) had been, to some degree, formally incorporated into current decision-making strategies. Two key reasons for using the information were stated. First, the project and, in turn, paper had been completed at the request of decision-makers and was, therefore, directly relevant to them. Second, the paper's findings supported current government polices.

Table R2e. Summary of decision-makers' awareness of paper

Mechanisms through which decision-makers became aware of paper	Respondents N (%)*
• Before paper completion (i.e., during completion of project addressed in paper)	
1. Project commissioned by decision-makers	6 (21)
2. Project committee/team included decision-makers	6 (21)
3. Project participants (i.e., study sample) included decision-makers	8 (28)
4. Informal discussions between author and his/her colleagues involved in decision-making	1 (3)
• After paper completion	
1. Author sent paper to decision-makers	9 (31)
2. Author contacted decision-maker(s) to discuss paper	7 (24)
3. Author presented paper at conference(s) attended by decision-makers	4 (14)
4. Author held seminar/workshop for decision-makers	6 (21)
5. Informal discussions between decision-makers involved in project and their colleagues	2 (7)
6. Paper published in journal(s)/document(s) read by decision-makers	8 (28)
7. Informal discussions between author and his/her colleagues involved in decision-making	3 (10)
8. Decision-makers' involvement in follow-up projects	1 (3)

*Percent based upon number of authors reporting that decision-makers were aware of his/her paper (n=29).
Note: Percentages do not total 100% since some authors provided more than one comment.

Table R2f. Summary of *how* and *why* decision-makers used papers

Usefulness of papers to decision-makers	Respondents N (%)*
Manner(s) in which information in paper was used by decision-makers	
• Formed basis for priority-setting "pilot" study	1 (5)
• Formed basis for program of research on priority-setting	1 (5)
• As a guide for implementing a priority-setting framework	2 (10)
• To develop priority-setting criteria/guidelines	4 (19)
• To revise current priority-setting criteria/guidelines	3 (14)
• Validate current priority-setting processes	1 (5)
• Formed basis for priority-setting exercises/processes	3 (14)
• Support current government policy/position	2 (10)
• Stimulate debate/discussion about current priority-setting policies	3 (14)
• Compare current priority-setting policies with those in other jurisdictions	1 (5)
Reason(s) decision-makers used information in paper	
• Directly relevant to certain decision-makers	
1. Based on project initiated at decision-makers' request	4 (18)
2. Based on project conducted in decision-makers' jurisdiction	2 (9)
3. Based on project that was part of local planning	2 (9)
• Supported current government policy/position	5 (23)
• Provided systematic approach to priority-setting	3 (14)
• Provided practical as opposed to theoretical information	1 (5)
• Presented in a simple, easily-understood manner	2 (9)
• Increasingly important issue in many health care jurisdictions (i.e., timeliness)	3 (14)

*Percent based upon number of authors reporting that decision-makers used his/her paper (n=18).

Note: Percentages do not total 100% since some authors provided more than one comment.

3. Key Informant Interviews

Key informants' responses regarding the role of the public and their values in priority-setting were grouped into 4 categories representing sequential phases of the priority-setting process: 1) Identification of potential needs, 2) Prioritization of needs identified, 3) Communication of priority-setting decisions to stakeholders, and 4) Response from stakeholders to priority-setting decisions. Current public involvement in the first phase (i.e., identifying potential health care needs) is presented in Table R3a. The most common approach initiated by RHA boards has been the assembly of advisory groups (i.e., Community Health Councils). To date, none of the provincial boards/committees have elicited public input. Of approaches initiated by the public, those consisting of contacting RHA board representatives or the provincial board/committee (either in-person, by telephone, or through writing letter) were employed most frequently (Table R2b). During priority-setting, itself (i.e., phase 2), key informants deemed input from board members elected by the public "public involvement". The types of information identified as contributing to the body of "evidence" upon which priorities were set included findings from formal needs assessments (i.e., phase 1) and board/committee's awareness of the public's acceptability or support for a specific "need" (Table R3c). Once priority-setting decisions were made, approaches used to communicate them (i.e., phase 3) to the public within RHAs engaged the media, as well as the decision-makers, themselves. In contrast, provincial boards/committees appeared to rely almost exclusively on the media. Regarding opportunities for the public to respond to and/or appeal decisions (phase 4), they primarily consisted of contacting a member of the Senior Management Team of the RHA or provincial boards/committees. According to key informants interviewed, most appeals received, at a minimum, a follow-up phone call or letter addressing the issue.

Key informants were also asked about the fairness of current priority-setting in their RHAs or provincial boards/committees. Almost all of them stated that, from a population health perspective, it was fair (Table R3d). In addition, they indicated mechanisms through which fairness has been achieved and maintained. Those related to the public included attentiveness to community concerns and public accessibility to decision-making criteria.

Lastly, key informants commented on the adequacy of the current role of the public in priority-setting and suggested ways in which it could be improved. While, in general, they indicated a need to better involve the public, they also expressed concerns regarding how best to ensure that such involvement does not become dominated by "special interest" groups. More importantly, key informants identified topics for which they would like to seek public input: 1) Reasonableness of the public's expectations for health services, 2) Separation of wants from needs, and 3) Alternative payment structures for pharmaceuticals

Table R3a. Approaches currently used to identify potential health care needs in Alberta

Stakeholder	Board/Committee-initiated: Approach used	RHAs N (%)	Provincial Boards/Committees N (%)	Stakeholder-initiated: Approach used	RHAs N (%)	Provincial Boards/Committees N (%)
Public	• Focus groups			• Contact (in-person, telephone, or written)		
	1 Randomly selected	1 (13%)	0 (0%)	1 Board/committee (administrative office)	1 (13%)	2 (67%)
	2 Non-randomly selected	3 (38%)	0 (0%)	2 Designated board/committee member representative	3 (38%)	1 (33%)
	• Stakeholder sessions	1 (13%)	0 (0%)	3 Through health care provider	2 (25%)	1 (33%)
	• Surveys			4 Provincial government representative (e g , MLA)	1 (13%)	1 (33%)
	1 Interviewer-administered (e g , telephone)	4 (50%)	0 (0%)	• Submission of Patient Complaints Report	1(13%)	1(33%)
	2 Self-administered (e g , mail-out)	2 (25%)	0 (0%)	• Completion of patient satisfaction questionnaires	1(13%)	0(0%)
	• Key Informant Interviews (community/municipal leaders)	1(13%)	0 (0%)	• Public Board Meetings		
	• Community Forums (includes town hall meetings)	3 (38%)	0 (0%)	1 Participation in open question/answer period	2(25%)	0(0%)
	• Advisory Groups (Community Health Councils, Public Liaison Committees, etc)	5 (63%)	0 (0%)	2 Presentation to Board	1(13%)	0(0%)
	• Public Board Meetings	2 (25%)	0 (0%)	• Requested Meetings	1(13%)	0 (0%)
	• Regular Meetings	3 (38%)	0 (0%)	1. Senior management and community health councils	1(13%)	0 (0%)
	1. Involving senior management* and community health councils	3 (38%)	0 (0%)	2 Senior management and non-health-related community councils	1(13%)	0(0%)
	2 Involving senior management* and non-health-related community councils	3 (38%)	0 (0%)	3 Senior management and municipal/ community leaders	1(13%)	0(0%)
	3 Involving senior management* and municipal/ community leaders	2 (25%)	0 (0%)	4 Involving elected board representative and public		
	4 Involving elected board representative and public					
Health Care Providers						
Physicians	• Focus Groups	1 (13%)	0 (0%)	• Contact (in-person, telephone, or written)		
	• Stakeholder Sessions	1 (13%)	1 (33%)	1 Board/committee (administrative office)	0 (0%)	1 (33%)
	• Key Informant Interviews	1 (13%)	0 (0%)	2 Designated board/committee member representative (Medical Director)	2 (25%)	2 (67%)
	• Surveys			3 Medical Director through specialty heads/chiefs/ supervisors	2 (25%)	1 (33%)
	1 Interviewer-administered (e g , telephone)	0 (0%)	0 (0%)	4 Provincial government representative	0 (0%)	1 (33%)
	2 Self-administered (e g , mail-out)	1 (13%)	0 (0%)	• Requested Meetings		
	• Forums	1 (13%)	0 (0%)	1 With designated board representative (e g , Medical Director) and/or senior management	1 (13%)	1 (33%)
	• Advisory Groups (e g , Physician Liaison Council)	5 (63%)	0 (0%)	2 With specialty heads/chiefs	1 (13%)	1 (33%)
	• Meetings	4 (50%)	0 (0%)			
	1 With designated board representative (e g , Medical Director) and/or senior management	1 (13%)	0 (0%)			
	2 With specialty heads/chiefs/supervisors					
Clinical Staff	• Focus Groups	1 (13%)	0 (0%)	• Contact (in-person, telephone, or written)		
	• Key Informant Interviews	2 (25%)	0 (0%)	1 Board/committee (administrative office)	0 (0%)	0 (0%)
	• Surveys			2 Designated board/committee member representative (Medical Director)	2 (25%)	0 (0%)
	1 Interviewer-administered (e g , telephone)	1 (13%)	0 (0%)	3 Medical Director through department supervisors/ managers/directors	3 (38%)	1 (33%)
	2 Self-administered (e g , mail-out)	1 (13%)	0 (0%)	• Requested Meetings		
	• Forums	1 (13%)	0 (0%)	1 With designated board representative (e g , medical director) and/or senior management	0 (0%)	0 (0%)
	• Advisory Groups	2 (25%)	0 (0%)	2 With department or site managers/supervisors/ directors	1 (13%)	0 (0%)
	• Medical Staff Meetings	3 (38%)	0 (0%)			
	1 With designated board representative (e g , medical director) and/or senior management	2 (25%)	0 (0%)			
	2 With department or site managers/directors					

*Senior-level RHA or provincial board/committee administration (e g , Chief Executive Officers, Vice-Presidents, Board Chairs, Board Members, etc)

Table R3b. Information currently considered during health care priority-setting in Alberta

Technical (Objective) Information		
Description of Information	RHAs N (%)	Provincial Boards/Committees N (%)
Jurisdictional Data		
• Health Services Utilization		
1. Waiting times	5(63%)	2(67%)
2. Service-specific utilization rates	6(75%)	2(67%)
3. Import-export data	3(38%)	0(0%)
• Demographic (eg population growth rates)	5(63%)	1(33%)
• Epidemiologic/population health status (e.g., disease/condition incidence, prevalence, morbidity, and mortality rates)	5(63%)	1(33%)
• Formal Needs Assessment Findings	8(100%)	2(67%)
Published Literature		
• Clinical efficacy and effectiveness studies* (both quality and quantity)	1(13%)	3(100%)
• Economic analyses (both quality and quantity)	1(13%)	2(67%)
• Clinical Practice Guidelines	3(38%)	3(100%)
• Theoretical frameworks/decision-making models	1(13%)	1(33%)
Expert Opinion	1(13%)	1(33%)

Non-Technical (Subjective) Information		
Description of Information	RHAs N (%)	Provincial Boards/Committees N (%)
• Resource availability		
1. Financial	8(100%)	2(67%)
2. Human	5(63%)	1(33%)
• Alignment with board/committee mission, vision, goals, and values (as outlined in business plan)	7(88%)	1(33%)
• Government direction (e.g., legislated regulatory requirements and ministerial mandates/directives)	8(100%)	3(100%)
• Current patterns of care (eg appropriateness of current access)	5(68%)	1(33%)
• Geographic remoteness of jurisdiction (e.g., access to services)	1(13%)	0(0%)
• Comparability with care offered in other jurisdictions (both within and outside of Alberta)	6(75%)	2(67%)
• Comparability with accepted benchmarks	3(38%)	1(13%)
• Public acceptability/support	5(63%)	(0(0%)
• Potential for increasing length and/or quality of life through improved:		
1. Quality of care	6(75%)	1(33%)
2. Access to care	4(50%)	0(0%)
• Potential impact on:		
1. Provision of complete continuum of health care (i.e., both health promotion/prevention programs and acute and continuing care)	3(38%)	1(33%)
2. Provision of health care for entire jurisdiction	6(75%)	1(33%)
• Health care organizational considerations		
1. Innovativeness and/or window of opportunity (e.g., potential to advance knowledge)	2(25%)	1(33%)
2. Effect on current health care delivery processes	3(38%)	1(33%)
3. Political implications	2(25%)	2(67%)
4. Ethical implications	2(25%)	1(33%)
• Cultural considerations of communities within jurisdiction	2(25%)	0(0%)
• Reliance on health care industry as source of income	2(25%)	0(0%)

*Senior-level RHA or provincial board/committee administration (e.g., Chief Executive Officers, Vice-Presidents, Board Chairs, Board Members, etc.)

Table R3c. Approaches currently used to disseminate priority-setting decisions and manage stakeholder responses in Alberta

Stakeholder Audience	Communication of priority-setting decisions: Approach used	RHAs N (%)	Provincial Boards/Committees N (%)	Response to priority-setting decisions: Approach used	RHAs N (%)	Provincial Boards/Committees N (%)
Public	• Distribution of official documents (to all residents or publicly accessible facilities)			Rationale/reasons for decisions		
	1 Annual reports and/or business plans	3(38%)	1(13%)	• Provided		
	2 Organization newsletters/handouts	4(50%)	1(13%)	1 Always	6(75%)	1(33%)
	• Community Forums (includes town hall meetings)	2(25%)	0(0%)	2 Sometimes	0(0%)	0(0%)
	• Public Board Meetings	5(63%)	0(0%)	3 Upon request	1(25%)	1(33%)
	• Senior management*-initiated contact with:			• Not provided	1(13%)	1(33%)
	1 Community health councils	3(38%)	0(0%)	Appeals of decisions		
	2 Non-health community/municipal councils	4(50%)	0(0%)	• Contact (in-person, written, or telephone)		
	3 Municipal/community leaders	1(13%)	0(0%)	1 Senior management*	5(63%)	1(33%)
	4 Patients potentially affected in community	1(13%)	0(0%)	2 Designated board/committee representative	1(13%)	0(0%)
	5 Constituents	2(25%)	0(0%)	3 Community Health Council	1(13%)	0(0%)
	• Posting on organization's web site	4(50%)	2(67%)	4 Government representative (MLA)	1(13%)	1(33%)
	• Media (television, radio, and/or newspaper) Announcements (through news releases and/or media attendance of public board meetings)	5(63%)	2(67%)	5 Health care provider	1(13%)	0(0%)
				6 Municipal council	1(13%)	1(33%)
				• Complete patient complaint form	3(38%)	0(0%)
				• Raise issue at public board meeting	1(13%)	0(0%)
				• Invite senior management to attend meeting	1(13%)	0(0%)
				Organization's response to appeals		
				• Follow-up phone call or letter about issue	1(13%)	1(33%)
				• Invitation to present at public board meeting	4(50%)	0(0%)
				• Invitation to meet privately with board/committee	2(25%)	0(0%)
Health care Providers						
Physicians				Rationale/reasons for decisions		
	• Direct distribution of official documents			• Provided		
	1 Annual reports and/or business plans	1(13%)	0(0%)	1 Always	5(63%)	1(33%)
	2 Organization internal newsletters/handouts	4(50%)	1(33%)	2 Sometimes	1(13%)	1(33%)
	• Senior management*-initiated contact with: (in-person, telephone, electronic, or written)			3 Upon request	0(0%)	0(0%)
	1 Physician advisory groups	5(63%)	1(33%)	• Not provided	2(25%)	1(33%)
	2 Designated physician representative	1(13%)	0(0%)	Appeals of decisions		
	• Meetings (between senior management (e.g., medical director) and specialty heads/chiefs/directors)	2(25%)	1(33%)	• Contact (in-person, written, or telephone)		
				1 Senior management* or sub-committee	1(13%)	1(33%)
				2 Physician advisory groups	1(13%)	0(0%)
				Organization's response to appeals		
				• Invitation to present to board/committee	1(13%)	0(0%)
				• Issue raised at next board meeting	1(13%)	0(0%)
Clinical Staff	• Distribution of official documents (to all residents or publicly accessible facilities)			Rationale/reasons for decisions		
	1 Annual reports and/or business plans	1(13%)	1(33%)	• Provided		
	2 Organization newsletters/handouts	5(63%)	1(33%)	1 Always	5(63%)	1(33%)
	• Staff Forums	1(13%)	0(0%)	2 Sometimes	1(13%)	1(33%)
	• Senior management*-initiated contact with: (in-person, telephone, electronic, or written)			3 Upon request	0(0%)	0(0%)
	1 Department mangers/program directors	3(38%)	0(0%)	• Not provided	2(25%)	1(33%)
	2 Advisory groups/management teams	4(50%)	0(0%)	Appeals of decisions		
	3 Front-line staff	1(13%)	0(0%)	• Contact (in-person, written, or telephone)	1(13%)	1(33%)
	• Staff Meetings			1 Senior management* or sub-committee	2(25%)	0(0%)
	1 With designated board representative	4(50%)	1(33%)	2 Advisory group (e.g., medical advisory committee)		
	2 Through department managers/directors	2(25%)	0(0%)	Organization's response to appeals		
				• Invitation to present to board/committee	1(13%)	1(33%)
				• Issue raised at next board meeting	1(13%)	1(33%)

Table R3d. Fairness of priority-setting process and approaches used to achieve fairness

Fairness of priority-setting process	RHAs N (%)	Provincial Board/Committees N (%)
From population health perspective		
• Yes	7 (88%)	3 (100%)
• No	1 (13%)	0 (0%)
Approaches used to achieve fairness		
• Before priority-setting (during identification of potential needs)		
1. Attentive to concerns of public within board/committee's jurisdiction	5 (63%)	0 (0%)
2. Board/committee membership represents all major stakeholder groups	2 (25%)	0 (0%)
3. Decision-making criteria made accessible to public	1 (13%)	0 (0%)
• During priority-setting		
1. Adhere to decision-making guidelines/policies/frameworks	3 (38%)	1 (33%)
2. Ensure entire board/committee is informed/educated	2 (25%)	0 (0%)
3. Ensure decisions are based upon best available evidence/information	3 (38)	0 (0%)
4. Ensure sufficient opportunity for open dialogue (i.e., debate and discussion) among board/committee members during decision-making	3 (38)	0 (0%)
5. Decisions generated from bottom up	2 (25%)	0 (0%)
6. Ensure decisions coincide with business plan	3 (38%)	1 (33%)
7. Decisions require complete board/committee consensus	1 (13%)	1 (33%)
• Once priority-setting decisions have been made		0 (0%)
1. Continually review and evaluate decisions/priorities	1 (13%)	1 (33%)
2. Respond to all appeals of decisions	2 (25%)	0 (0%)

DISCUSSION AND IMPLICATIONS

There are essentially four independent components to this study. The information from each has different implications, as far as developing priority-setting processes in this province is concerned, or considering future research. Therefore, for the purposes of this report, the four components are discussed separately, with associated suggestions for implementation and research presented where relevant.

1. Literature Review

The first part of this study was a "State of the Science" review of published and grey literature on priority-setting in health care and the role of public involvement. The review shows widespread recognition of the need for explicit priority setting in health care (at national, regional and community levels) over recent years. There are numerous published examples of processes for priority-setting and rationing in various countries, at these levels. At national levels, most of the work has involved trying to articulate publicly acceptable guiding principles for priority-setting. At the regional and community levels, the focus has been narrower, and aimed at establishing systematic approaches to setting priorities explicitly for services and programs. (ie identifying services as opposed to identifying principles upon which the identification would be done).

The literature reflects an agreement that health care resource allocation decision making (or priority setting or rationing) must be values-based and the processes used must accommodate the values of citizens within a specific nation, region, or community. Technical information is necessary, but not sufficient. At regional or community levels, factors important for priority setting will vary from place to place, as will the processes for obtaining public input on which factors are important, and for involving the public in decision-making. From the literature, a number of relevant factors were identified: population needs, equity, costs, effectiveness of interventions or technologies, health status, severity and nature of the disease, potential for health gain, socioeconomic status (e.g., income and social class), age, and cause of disease or condition (e.g., self infliction due to lifestyle choices). Processes used or proposed to capture public values include: surveys (telephone, mail or in-person), focus group sessions (one-time or periodically), panel sessions, town hall meetings, forums, and citizens'juries. No one generic process appears to be regarded as universally applicable.. Further, a combination of techniques, which tends to capture more perspectives and facts, is preferred.

Implications for implementation in Alberta

The literature shows that little has been reported in Alberta on systematic priority setting in health care. There are examples of models which have been used elsewhere which should be introduced into the province. Demonstration projects ought to be conducted. Since most of what has been done elsewhere has not undergone much evaluation, any such project must also be evaluated. It should be possible to implement such projects in different regions, and settings. For example, a citizens' jury could be used to try and determine the principles that should be used in a provincial pharmaceutical formulary decision making process, and to ascertain what level of financial burden individuals would be prepared to assume for pharmaceuticals. Different forms

of representative groups of the public could be created in different regions struck with the task of creating a priority setting process, or to help in prioritizing broad service

Implications for future research
Very little in the way of formal evaluation of the various models described in the literature has been reported. A first step would be to undertake a secondary synthesis of the literature critiquing models proposed and used. This includes editorials, commentaries, policy analyses, and some formal critiques. This body of literature was beyond the scope of the present study. There is also methodological research that could be conducted (eg in the area of economic analysis to support decision making, such as adjusting QALYs for factors important to the public, and further refining the Program Budget and Marginal Analysis method). Some of the demonstration projects of the type described in the previous paragraph could also form the basis for legitimate research studies, (eg studies of the optimal composition of representative groups used to elicit public values or to aid priority setting in specific circumstances). In addition, research examining the appropriate qualitative techniques for collecting and analyzing data, to ultimately ensure the validity of any work completed, should also be supported.

The legal literature was also reviewed. It focused on jurisprudence (published judicial decisions or legal cases) because of their power to compel policy-making, and the precedential weight of these court decisions for future decisions.

The relatively small number of Canadian court decisions in which health care priority-setting issues are referenced as part of the reasons for decision, and the disparate facts that engage these issues, make generalized conclusions difficult. However, it is reasonably clear from the review that Canadian courts traditionally have taken a 'hands off' approach to health care priority-setting, and have not scrutinized the evidence relied on by policy makers in taking those decisions, unless the policy-makers have exceeded their legislative jurisdiction or the policy has violated fundamental rights or freedoms protected by the Charter. However, the judicial response to increasingly frequent and aggressive Charter challenges of denial of access to specific health services suggests the beginning of a more activist trend. Conversely, court decisions in malpractice litigation do not suggest that priority-setting issues are becoming more significant in that context, to this point at any rate.

Implications for implementation in Alberta
If the trend is towards more judicial scrutiny of evidence around priority-setting, and as health care priority-setting issues become more prevalent in constitutional, administrative and private law proceedings before Canadian courts, judges will benefit from and may want to be educated about how these issues are working through by policy-makers. There are established judicial education organizations, such as the National Judicial Institute, that would likely be interested in proposals in this area.

Implications for future research
Three projects would be useful in relation to the legal literature. Firstly, this review was limited to published decisions of Canada courts. It did not include other, extra-judicial legal proceedings like public inquiries or fatality inquiries, in which priority-setting issues may have been considered relevant and evidence presented. This would be a useful addition to the legal literature on the subject. Secondly, this review did not go beyond the published decisions to

investigate whether priority-setting issues were raised and/or evidence was presented that were not referenced in the published decisions. A systematic review of the 'public domain' court files for each of the cases identified in this study (which should reveal all of the documentary evidence, and written arguments, presented to the Court), and surveys or interviews with lawyers and/or judges who gave or heard arguments in these cases, may give greater insight into why evidence does not appear to be figuring prominently in the jurisprudence. Thirdly, a survey of judicial awareness of attitudes towards priority-setting issues could be an extremely useful tool for identifying educational programs and future legal trends.

2. Authors' Survey

The second part of the study was intended to ascertain the "utility" or value of the reviewed research in actual decision-making. It is noteworthy that the response rate for the surveys was high. This indicates that researchers undertaking this type of investigation are, themselves, keen on ensuring that their results get used. Thus, from a "supply" side view, there is interest in having the research taken up by decision makers. Also, several of the authors were decision makers, with an active interest in the "real world" impact of their work. A number of the studies had been used in priority setting-related activities (e.g., instituting an actual process, developing guidelines, etc.). In general, whether they were used in decision making depended on process factors (e.g., whether or not the study's team of investigators included a relevant decision maker) and factors external to the study (e.g., whether or not the study's results supported the government's present position).

Implications for implementation in Alberta
Decision makers needing to develop priority setting processes that could stand up to scientific scrutiny (and be more applicable in the province) must ensure that they are involved in the project from its inception. Also, it would be important to have these decision makers as co-authors of any publications that result, as that is associated with better receptivity of the study among other decision makers.

Implications for future research
The findings from these surveys are applicable beyond the area of priority setting. As alluded to above, any policy research directed to inform decision making must involve the decision maker from the outset. The research program that might emerge from this State of the Science Review must have this as a prerequisite for funding. In addition, a study examining the "utility" of commissioned reports (as opposed to peer-reviewed papers, which often take a longer period to become available, and, more importantly, were the focus of the authors' surveys) should be conducted.

3. Key Informant Interviews

The interviews indicate that there is no common, systematic approach to priority setting in the provincial health authorities. Three sets of factors need to be considered. First, there appears to be a strong view among most Boards that better, more timely access to data and information is needed to help establish priorities in an evidence-based manner. Second, there are aspects internal to the organization (such as the roles/responsibilities of the medical staff, communications, and information management) that vary from region to region. These will

influence the success of any systematic and formalized priority setting process. Third, there are external factors (annual basis for funding by government, the government's role in defining "core services", etc.) that will impinge upon an RHA's ability to more effectively set priorities. With respect to public involvement in such activities, while examples of public consultation exist, no consensus regarding the extent to and manner by which the public ought to be involved is evident.

This study has shown that various models of priority-setting and the public's role in it exist. Specifically, health authorities/districts in the UK have had the greatest amount of experience in this area. When the proposal for this study was submitted to AHFMR, it was expected that options for improving priority-setting practices and defining the public's roles would be presented to two Alberta decision makers at the end of the project in order to obtain feedback on the relative feasibility, applicability and usefulness of the various methods. However, this was not completed due to time constraints. Based on the interviews, the following suggestions are made, nonetheless.

Implications for implementation in Alberta
A two-day "event", involving the provincial health delivery boards and the department of Health and Wellness, facilitated by an independent organization should be held. The objective of this would be to reach consensus on the elements of a standardized process for priority-setting and involving the public in Alberta. The agenda would include a detailed discussion of the factors that might be impediments to creating a standard process, such as the three categories mentioned in the previous section. Following this, a presentation of some possible solutions (by experts from the UK, and perhaps New Zealand), and a summary of this particular study will be made.

Implications for future research
In order to determine the willingness of the public in Alberta to be involved much more closely with priority setting, research will need to be completed. This will be to determine the willingness of citizens to commit their time and effort, and more importantly, to establish their willingness to participate in trade-off decisions, which could affect access to certain types of care for specific individuals or groups. The outcomes would include the explicit types of decisions that members of the public would be prepared to be confronted by (in participating with RHAs on priority setting), and the level of decision that is acceptable to them (e.g., establishing criteria for priority setting as opposed to choosing between packages of services).

RECOMMENDATIONS

1. A two-day decision-makers' forum to share the results of this review and obtain agreement on next steps for incorporating public values into decision-making should be held.

2. A consortium of decision-makers and researchers should be developed in order to select and conduct demonstration projects designed to engage the public in priority-setting.

3. A survey of decision-makers to assess the usefulness of papers cited in this review and identify gaps in existing research should be performed.

4. Research on the willingness of individuals to participate in priority-setting at various levels, including those which require making trade-off decisions between groups, should be conducted.

5. A more detailed review pertaining to what is known about public involvement in decision-making with a more precisely defined scope should be completed.

6. Research into the utility of commissioned reports for decision-makers should also be conducted.

7. Existing methodological research on economics-based processes for priority-setting and their
impact should be more thoroughly examined.

8. Criteria for appraising the quality of priority-setting studies should be developed.

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APPENDIX A

Data Abstraction Forms

State of the Science Review: Incorporating public values and technical information into health care resource allocation decision-making

Priority-Setting Literature Data Abstraction Form

Title of paper:_____ Date reviewed:_____
_____ Date published:_____

First Author: _____ Country:_____

1. Paper classification:	☐ Priority-setting – hypothetical ☐ Priority-setting – actual
Descriptive Information	
1. What was the purpose of the paper?	
2. What method(s) for priority-setting was/were described?	
3. Who comprised the "sample" population?	
4. What was the setting for the study/exercise?	
5. What were the results?	
6. What conclusions were drawn?	
7. What implications were presented?	
Quality Appraisal Criteria	
1. Was the research question clearly identified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated
2. Was an explicit account of the theoretical framework and methods used at every stage of the research given?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable

3. *Was the context clearly described?*	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
4. Was the sampling strategy clearly described and justified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
5. Was the sampling strategy theoretically comprehensive to ensure the generalizability of the conceptual analyses (e.g., diverse range of individuals and settings)?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
6. Was the fieldwork described in detail?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
7. Was the evidence (fieldwork notes, interview transcripts, recordings, documentary analysis, etc.) independently inspected by others?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
8. If relevant, was the process of transcription independently inspected?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
9. Were the procedures for data analysis clearly described and justified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
10. Did data analysis relate to the original research questions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
11. How were the themes and concepts identified from the data?	☐ Using grounded theory ☐ Using content analysis ☐ Other:
12. Was the analysis repeated by more than one researcher to ensure reliability?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
13. Did the researcher make use of quantitative evidence to test qualitative conclusions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable

14. Did the investigator give evidence of seeking out observations that might have contradicted or modified the analysis?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
15. Was the evidence presented systematically in the written account to satisfy the skeptical reader of the relationship between the interpretation and the evidence?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
Fairness of Priority-setting Approach	
1. Is rationale for priority-setting decisions stated?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
2. Are reasons based on information that appears to be reasonable, given the priority-setting context?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
3. Are priority-setting decisions accessible to the public?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
4. Are reasons for priority-setting decisions accessible to the public?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
5. Is there a formal process for appealing decisions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
6. Is there an informal process for appealing decisions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
7. Is there a regulatory mechanism in place to ensure the above conditions are met?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable

State of the Science Review: Incorporating public values and technical information into health care resource allocation decision-making

Public Values Literature Data Abstraction Form

Title of paper:_____ Date reviewed:_____

_____ Date published:_____

First Author:_____ Country:_____

1. Paper classification:	☐ Public Involvement - Actual ☐ Public Involvement – Hypothetical ☐ Public Involvement - Conceptual
Descriptive Information	
1. What was the purpose of the paper?	
2. What method(s) for involving the public was/were described?	
3. Who comprised the public "sample" population?	
4. What was the setting for the study/exercise?	
5. What were the results?	
Quality Appraisal Criteria	
1. Was the research question clearly identified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated
2. Was an explicit account of the theoretical framework and methods used at every stage of the research given?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
3. Was the context clearly described?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
4. Was the sampling strategy clearly described and justified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable

5. Was the sampling strategy theoretically comprehensive to ensure the generalizability of the conceptual analyses (e.g., diverse range of individuals and settings)?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
6. Was the fieldwork described in detail?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
7. Was the evidence (fieldwork notes, interview transcripts, recordings, documentary analysis, etc.) independently inspected by others?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
8. If relevant, was the process of transcription independently inspected?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
9. Were the procedures for data analysis clearly described and justified?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
10. Did data analysis relate to the original research questions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
11. How were the themes and concepts identified from the data?	☐ Using grounded theory ☐ Using content analysis ☐ Other:
12. Was the analysis repeated by more than one researcher to ensure reliability?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
13. Did the researcher make use of quantitative evidence to test qualitative conclusions?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
14. Did the investigator give evidence of seeking out observations that might have contradicted or modified the analysis?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable
15. Was the evidence presented systematically in the written account to satisfy the skeptical reader of the relationship between the interpretation and the evidence?	☐ Yes ☐ No ☐ Don't know ☐ Not stated ☐ Not applicable

APPENDIX B

Authors' Survey Information Letter and Questionnaire

AUTHORS' SURVEY INFORMATION LETTER

Title of Project: Incorporating Public Values and Technical Information into Health Care Resource Allocation Decision-Making

Principal Investigator:
Dr. Devidas Menon — Institute of Health Economics — (780) 448-4881
Department of Public Health Sciences, University of Alberta

Co-Investigators:
Timothy Caulfield — Health Law Institute — (780) 492-8358
Department of Public Health Sciences, University of Alberta

Dr. Douglas Martin — Joint Centre for Bioethics — (416) 978-6926
Health Policy, Management and Evaluation, University of Toronto

Dr. Peter Singer — Joint Centre for Bioethics — (416) 978-4756
Health Policy, Management and Evaluation, University of Toronto

Brent Windwick — Health Law Institute — (780) 492-6127
Faculty of Law, University of Alberta

Project Coordinator:
Tania Stafinski — Institute of Health Economics — (780) 448-4881

--date--

Dear Author:

You are being asked to take part in a study that will look at how previous research on priority-setting has affected health care policy and decisions.

In general, the demand for health services is greater than the amount of resources available to provide them. As a result, those involved in setting health care priorities must choose which services to pay for through the publicly-funded system. To ensure that the 'right' decisions are made, there has been a shift towards evidence-based decision-making. The main source of information for this evidence base is past research on how priority-setting *is* done and how it *should* be done.

Purpose of the study

The purpose of the study is to determine the usefulness of existing research on priority-setting to decision-makers responsible for allocating health care resources.

Background

Last year, provincial agencies that fund health research met with regional health care providers, managers, and researchers to identify important topics for programs of research aimed at informing policy and decision-making in the province. To help guide the planning of programs, an overview of past research, as well as local policies related to each topic was sought. Once completed, these overviews will be used to determine information gaps that may be filled through the programs of research. They will also provide a knowledge base to assist current decision-makers.

One of the topics identified was the role of factors such as public values in setting health care priorities.

Participation in the study

You will be asked to complete the survey that is attached to this information letter. This survey contains questions about how the research described in your paper entitled "_____" affected health care policy and decisions. It will take approximately 10 minutes to complete. You will then be asked to return the survey by e-mail (tstafinski@ihe.ab.ca) or fax ((780) 448-0018).

Possible benefits to you and others

By taking part in the study, you will be sharing your research and its impact with others who are currently working in the same area. This may lead to future research partnerships.

Findings from the survey will be used in planning future research to improve priority-setting in Alberta.

Possible risks

There are no expected risks involved in taking part in the survey.

Confidentiality and voluntary participation

You will be assigned a confidential identification number. Therefore, your name will not appear on the survey. All information will be held private, except when professional codes of ethics or legislation requires reporting. Only the project's investigators and coordinator will have access to completed surveys.

The information you provide will be kept for at least five years after the study is done. This information will be kept in a secure area (i.e., locked filing cabinet). Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results.

The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

You are free not to participate in the survey. You are also free to withdraw from the study at any time. The decision not to participate or to withdraw will, in no way, affect or job or academic standing. You have the right to refuse to answer any questions. You do not have to give a reason.

Further information about the study

If you have any questions or would like further details about the survey, please contact: Tania Stafinski at (780) 448-4881 or Dr. Sharon Warren, Chair of the Health Research Ethics Board: Panel B, (who is not involved in the survey) at 492-7856.

Author Identification Number:_____

SURVEY OF AUTHORS

Instructions:

Please complete each of the following questions about your paper, entitled: "----------" by placing a check mark in the appropriate box or writing your answer in the space provided.

Please return the completed survey to the project coordinator by fax or e-mail using the address:

E-mail address: tstafinski@ihe.ab.ca
Fax number: (780) 448-0018

1. Which category best describes your paper?

Type of paper

1. Demonstration project (e.g., studies based on scenarios using hypothetical or actual data) 9

Main topic: *Public values* 9

Priority-setting

2. Actual priority-setting exercise (e.g., case studies in hospitals) 9

3. Other (specify)_____ 9

2. Are any relevant decision-makers aware of your paper?

Yes 9 How do you know this?_____

_____

No 9 How do you know this?_____

_____

Don't Know 9 Not applicable

If you answered "**yes**" to question **2**, go to question **3**.
If you answered "**no**" or "**don't know**" to question **2**, **skip** question **3** and go to question **7**.

3. How did decision-makers become aware of your paper?

_____
_____
_____
_____
_____
_____
_____

4. Was the information from your paper used by decision-makers?

Yes 9 How do you know this?_____
_____

No 9 How do you know this?_____
_____

Don't Know 9 Not applicable

If you answered "**yes**" to question **4**, go to question **5**.
If you answered "**no**" to question **4**, **skip** question **5** and go to question **6**.
If you answered "**don't know**" to question **4**, **skip** questions **5 and 6** and go to question **7a**.

5. In what way(s) was/were the information from your paper used by decision-makers?

_____
_____
_____
_____
_____
_____
_____

6. Why do you think the information was/was not used by decision-makers?

_____

_____

_____

_____

_____

_____

_____

7a. Have you written *other* papers related to this one? This includes non-peer-reviewed and peer-reviewed papers.

Yes	9
No	9

If you answered "**yes**" to question **7a**, go to question **7b**.
If you answered "**no**" or "**don't know**" to question **7a**, **stop** here.

7b. Please list the papers below.

	Title of paper	Authors	Publication Date	Published in:
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				

Thank you for participating in the survey.

APPENDIX C

Key Informant Information Letter and Interview Questions

KEY INFORMANT INFORMATION LETTER

Title of Project: Incorporating Public Values and Technical Information into Health Care Resource Allocation Decision-Making

Principal Investigator:
Dr. Devidas Menon — Institute of Health Economics — (780) 448-4881
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Health Policy, Management and Evaluation, University of Toronto

Brent Windwick — Health Law Institute — (780) 492-6127
Faculty of Law, University of Alberta

Project Coordinator:
Tania Stafinski — Institute of Health Economics — (780) 448-4881

---date---

Dear ( ):

You are being asked to take part in a study that will look at health care priority-setting and how public values affect decisions.

In general, the demand for health services is greater than the amount of resources available to provide them. As a result, those involved in setting health care priorities must choose which services to pay for through the publicly-funded system. To ensure that the 'right' decisions are made, there has been a shift towards evidence-based decision-making. The main source of information for this evidence-base is past research on both how priority-setting *is* done and how it *should* be done. However, in recent years, public interest in health care has grown, making it clear that evidence, by itself, cannot drive decisions. The public now expects that their views will also be considered.

Purpose of the study

The purpose of the study is to describe methods for setting local health care priorities and determine whether or not they involve public values.

Background

Last year, provincial agencies that fund health research met with regional health care providers, managers, and researchers to identify important topics for programs of research aimed at informing policy and decision-making in the province. To help guide the planning of programs, an overview of past research, as well as local policies related to each topic was sought. Once completed, these overviews will be used to determine information gaps that may be filled through the programs of research. They will also provide a knowledge base to assist current decision-makers.
One of the topics identified was the role of factors such as public values in setting health care priorities.

Participation in the study

You will be asked to take part in a one-on-one, in-person interview. The interview will contain questions about how priority-setting decisions are made. The interview will be carried out at your workplace by a trained health services researcher. It will take approximately one hour to complete.

To make sure that your answers are correctly interpreted, all interviews will be audio-taped and then transcribed. Copies of information from questionnaires and transcripts will be given to you. You will be asked to review the accuracy of this information.

Possible benefits to you and others

By taking part in the study, you will be able to identify information that may help you in making decisions.

Findings from the study will be used in planning future research to improve priority-setting in Alberta.

Possible risks

There are no expected risks involved in taking part in the study.

Confidentiality and voluntary participation

You will be assigned a confidential identification number. Therefore, your name will not appear on the interview questionnaire. All information will be held private, except when professional codes of ethics or legislation requires reporting. Only the project's investigators and coordinator will have access to data from interviews.

The information you provide will be kept for at least five years after the study is done. This information, including transcriptions from audio-tapes, will be kept in a secure area (i.e., locked filing cabinet). Your name or any other identifying information will not be attached to the information you gave. Your name will also never be used in any presentations or publications of the study results.

The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

You are free not to participate in the interviews. You are also free to withdraw from the interview at any time. The decision not to participate or to withdraw will, in no way, affect or job. You have the right to refuse to answer any questions. You do not have to give a reason.

Further information about the study

If you have any questions or would like further details about the study, please contact: Tania Stafinski at (780) 448-4881 or Dr. Sharon Warren, Chair of the Health Ethics Review Board: Panel B (who is not involved in the study) at 492-7856.

Your consent

Your signature on the consent form indicates that you understand the information about participation in the study and that you agree to be involved.

Please keep these pages for future reference.

I have read the above information letter.

_____Initials of study participant (key informant)

_____Initials of researcher

KEY INFORMANT INTERVIEW QUESTIONS

Questions:

1. Describe how priority-setting decisions are made by your regional health authority/provincial health board. (We are interested here in higher level decisions related to strategic directions and new programs/services.)

2. Describe your role in priority- setting based on the process you identified in question 1. Can you me some examples?

3. What factors (information or values) are typically considered during priority- setting? Please give examples.

4. What factors do you consider to be important for priority -setting and why? Please give examples.

5. How are priority-setting decisions communicated to others in the health region/provincial health board? Are the reasons for the decisions also communicated to others?

6. Is there an appeal process for someone who disagrees with the decision or process? If so, please describe it.

7. Do you think that the current priority- setting process is fair? Give reasons. If not, how do you think it could be improved?

8. How is the fairness of the priority-setting process maintained?